Research Report 370

**Emmanuel Okwara Kalu**

# Towards bettering HIV/AIDS understandings: A phenomenographic-comparison of the conceptions of HIV-positive university students in Finland and Nigeria

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## Abstract

More than half of those newly infected with HIV/AIDS are between the ages of 15 and 24 (UNICEF, UNAIDS and WHO 2002). The disease's challenge is not limited to students already diagnosed with the disease, but also to students in limbo (students who do not know their status), because about 50% of those living with HIV do not know their status (UNAIDS 2012). However, voluntary HIV screening is unpopular, probably due to fear and gross misconceptions. Based on the presumption that besides its health and educational impacts, the disease also influences the productivity and future goals of students, this study investigated and compared the conceptions of HIV-positive university students in Finland and Nigeria in search of not only the negative, but also the positive meanings of living with the disease, with the aim of bettering HIV/AIDS understandings. The study is primarily approached through phenomenography. Seven individuals participated in the study (three Finns and four Nigerians) through in-depth and e-mail interviews. The outcomes are described and compared under 7 main categories, 26 sub-categories and 300 themes based on the similarities and qualitative differences in the participants' conceptions. To further illustrate the outcomes, 'Concept Maps' were used at the end of each main category to separately show the Finnish and Nigerian participants' responses within each category. In addition, tables of comparison were used in Appendixes one to seven to compare the Finnish and Nigerian participants' conceptions thematically and also in relation to the results of earlier studies. Subsequently, propositions in text format were used in Appendix eight to present the concept map outcomes in a different light.

The findings reveal that although the negative effects are much more noticeable, the positive impacts are increasing. They add to refuting what we already know about living with the disease, especially in the 1980s and 1990s. In view of the many benefits of living with HIV, as illuminated by this study, the current

situation is unlike the past, as today living with HIV does more good than harm – especially in terms of motivating positive and healthful living. The comparison of the two groups reveals no wide gap between the Finnish and Nigerian participants' conceptions; nevertheless, while the Finnish participants are slightly better informed about HIV/AIDS, their Nigerian counterparts are more open and positive about their conditions. Due to the nature of its findings, the implications of this study are many; the most outstanding of which is that it may positively and healthfully transform readers. By bringing into the spotlight the unpopular positive sides of living with HIV (not AIDS), PLWHA could further be strengthened to cope with the disease, and the fears of students in limbo due to misconceptions could be reduced, which may motivate them to voluntarily participate in HIV screening. Furthermore, the study may contribute to enabling HIV/AIDS organisations to better tailor their services towards meeting the needs of their subjects. School authorities could equally be motivated to make school environments more HIV/AIDS friendly. The Finnish Ministry of Social Affairs and Health and similar ministries in other countries may also find in these outcomes reasons to push for changes in HIV/AIDS policies.

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*Keywords:* HIV/AIDS, PLWHA, students, education, health, healthful living

Helsingin yliopisto, Käyttäytymistieteellinen tiedekunta
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Sarjan nimi 370

**Emmanuel Okwara Kalu**

# Ymmärrysten edistäminen HIV/AIDS:sta: suomalaisten ja nigerialaisten HIV-positiivisten yliopisto-opiskelijoiden käsitysten fenomenografinen vertailu

## Tiivistelmä

HIV/AIDS on suuri haaste opiskelijoille. koska enemmän kuin puolet tartunnan saaneista on iältään 15 – 24 vuotiaita (UNICEF; UNAID and WHO 2002). Haasteellista on se, että suunnilleen 50 prosenttia opiskelijoista, joilla on HIV, ei tiedä, että he ovat saaneet HIV-tartunnan (UNAIDS 2012). Monet opiskelijat eivät ole menneet HIV-testiin, koska heillä on paljon virheellisiä käsityksiä tästä taudista. Vaikka tämä ongelma tiedetään, niin suurin osa HIV/AIDS-tutkimuksista kohdistuu sairauden ennalta ehkäisyyn. On tärkeää tutkia myös millaisia käsityksiä HIV/AIDS:iin sairastuneilla on, jotta voidaan vähentää väärinkäsityksiä. Tässä tutkimuksessa oletetaan, että opiskelijoiden käsitykset vaikuttavat heidän terveyteensä ja opiskeluunsa sekä heidän tulevaisuuden tavoitteisiinsa ja heidän toimintansa tuloksellisuuteen., Tämä tutkimus vertailee HIV-positiivisten opiskelijoiden käsityksiä Suomessa ja Nigeriassa. Tutkimuksessa verrataan suomalaisten ja nigerialaisten yliopisto-opiskelijoiden käsityksiä HIV/AIDS:sta. Koetetaan saada esiin sekä negatiivisia että positiivisia sairastuneena elämisen merkityksiä. Tutkimuksen tavoitteena on parantaa erityisesti HIV-positiivisten opiskelijoiden ymmärrystä HIV/AIDS:sta, tiesivätpä he sairastavansa sitä tai eivät vielä tiedä. Tutkimuksessa käytetään fenomenografiaa. Tutkittavina on seitsemän opiskelijaa, joista kolme on suomalaista ja neljä nigerialaista. Tutkimuksessa käytettiin sekä syvähaastattelua että sähköpostihaastattelua. Aineistoa analysoitaessa saatiin seitsemän pääkategoriaa, 26 alakategoriaa ja 300 teemaa, jotka perustuvat tutkittavien käsitysten samanlaisuuteen ja erilaisuuteen. Tulosten kokoamiseen ja havainnollistamiseen käytettiin käsitekarttoja kunkin pääkategorian lopussa. Liitteinä on seitsemän vertailutaulukkoa, joissa verrataan suomalaisten ja nigerialaisten tutkittavien käsityksiä teemoittain ja myös suhteessa relevanttiin tutkimuskirjallisuuteen. Kahdeksannessa liitteessä on käsitekarttojen avulla luotu propositioiden luettelo, jonka avulla muodostuu uudesta näkökulmasta käsitys tutkimuksen tuloksista. Tulokset osoittavat, että on HIV-sairaus vaikuttaa todella negatiivisesti siihen sairastuneiden elämään.

Vastaavia tutkimustuloksia on saatu aikaisemminkin. Mutta tutkimuksen tuloksena on myös se, että kielteisten vaikutusten lisäksi on lisääntyvä määrä koettuja positiivisia vaikutuksia HIV:iin sairastumisen kautta. Näitä ei kuitenkaan ole AIDSiin sairastuneilla. Kuten muutamissa uusissa HIV/AIDS-tutkimuksissa, tässäkin tutkimuksessa päädytään siihen, että tämän sairauden kanssa eläminen on hyvin toisenlaista kuin 1980- ja 1990-luvuilla. Tämän tutkimuksen tuloksissa nousee esiin, että toisin kuin aikaisemmilla vuosikymmenillä, nykyään HIV tekee enemmän hyvää kuin vahinkoa – erityisesti sairaus motivoi positiiviseen ja terveelliseen elämään. Tulokset myös osoittavat, että HIV-positiivisten opiskelijoiden käsitykset vastaavat nykyisin vallitsevia tieteellisiä käsityksiä HIV/AIDS:sta. Suomalaisten ja nigerialaisten käsitykset HIV/AIDS:sta eivät juuri eroa toisistaan. Merkittävin ero on siinä, että suomalaisilla on hieman enemmän tietoa HIV/AIDS:sta, mutta nigerialaiset vaikuttavat olevan avoimempia ja myönteisimpiä sairautensa suhteen. Tutkimuksen tuloksilla on monia seurauksia. Suurin niistä saattaa olla, että ne muuttavat myönteisesti ja terveyttä edistävästi lukijaa, kuten ne muuttivat tutkijaa. Tuomalla esiin HIV-sairauden positiiviset vaikutukset opiskeluun ja terveyteen (emotionaalisesti/henkisesti, fyysisesti ja sosiaalisesti), toiminnan tuloksellisuuteen ja tulevaisuuteen suuntautumiseen, voitaisiin HIV/AIDS:iin sairastuneiden voimia lisätä sairauden suhteen. Sellaisia opiskelijoita, jotka eivät tiedä sairastavansa HIViä, mutta, jotka ovat epävarmoja siitä, onko heillä se vai ei ole, voitaneen motivoida menemään HIV-testiin. Edelleen tulokset saattavat edistää sitä, että HIV/AIDS-organisaatiot räätälöivät palvelunsa paremmin vastaamaan asiakkaittensa tarpeita. Oppilaitosten hallinnosta vastaavia tulokset voivat motivoida tekemään oppilaitoksistaparemmin HIV/AIDS-sairaille sopivia. Edelleen tuloksista lienee hyötyä Suomen Sosiaaliministeriölle ja vastaaville ministeriölle muissa maissa HIV/AIDS:iin liittyvien toimintojen parantamisessa.

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*Avainsanat:* HIV/AIDS, PLWHA, käsitykset, opiskelijat, koulutus, terveys, terveellisesti eläminen

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*Helsinki, 27. 3. 2015*
*Emmanuel Okwara Kalu*

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## ABBREVIATIONS

**ARV:** Anti Retro Viral [Drugs]

**BBC:** British Broadcasting Corporation

**CDC:** Center for Disease Control [and Prevention]

**CHD:** Coronary Heart Disease

**CVD:** Cardiovascular Disease

**DUI:** Driving under the Influence of Alcohol

**EU**: European Union

**FDA:** Food and Drug Administration

**HAART:** Highly Active Antiretroviral Therapy

**HHES:** Home Health Education Service

**HIV/AIDS:** Human Immunodeficiency Virus or Acquired Immune Deficiency Syndrome

**IV Drug:** Intravenous Drug

**KELA:** Social Security Insurance

**NMFS:** Nigeria Malaria Fact Sheet

**OCED:** Organisation for Economic Co-operation and Development

**PE:** Physical Exercise

**PI:** Protease Inhibitor

**PISA:** Programme for International Student Assessment

**PLWHA:** People (Person) Living with HIV/AIDS

**PLWH:** People (person) Living with HIV

**SIV:** Simian Immunodeficiency Virus

**STIs:** Sexually Transmitted Infections

**TB:** Tuberculosis

**THL:** Finnish National Institute of Health and Welfare

**UN:** United Nations

**UNDESA:** United Nations Department of Economic and Social Affairs

**UNESCO:** United Nations Educational, Scientific and Cultural Organization

**VAT:** Value Added Tax

**WCHE:** Weimar Center of Health & Education

**WIHE:** Weimar Institute of Health and Education

**WHO:** World Health Organisation

**YLE:** Finnish Broadcasting Company

# 1 INTRODUCTION

## 1.1 Overview

HIV/AIDS (Human Immunodeficiency Virus or Acquired Immune Deficiency Syndrome) was discovered in the early 1980s, and ever since then the world has never remained the same. But besides the disease`s threats on health priorities in both developed and developing countries (UN 1987), many (including literates) only see HIV/AIDS as a highly infectious killer disease whose carriers are dangerous and must be avoided at all cost. As such, the disease is often talked about in secrecy. So in many settings, mentioning 'HIV/AIDS' alone sends shockwaves probably because many do not know if their past carefree lifestyles have already exposed them to it, and yet they lack the willingness to go for HIV screening mostly due to unpreparedness to be pronounced 'HIV-positive'.

The number of people living with HIV (PLWH) worldwide grew in 2008 to an estimated 33.4 million; this estimate is 20% higher than what it was in 2000, and the prevalence three times the equivalence in 1990 (UNAIDS/ WHO 2009), as such it is an epidemic. But besides the above trend, what further differentiates HIV from other chronic diseases is that it is often diagnosed during prime or youthful age. Going by a joint publication by UNICEF, UNAIDS and WHO titled: "*Young people and HIV/AIDS: Opportunity in crisis*", more than half of those newly infected with HIV are between ages 15 and 24, more than 60% of which are ladies (UN Women 2011a). The statistics also show that nearly 6,000 youngsters within the age brackets become infected with HIV each day, which is why an estimated 11.8 million youth are living with HIV/AIDS (UNICEF, UNAIDS and WHO 2002).

The above statistics show that indeed young people`s opportunities are in crisis, and going by the trend, it seems the proportion of new infection within the age bracket will continue to increase; while as ideally at age 15 a young person should have completed ninth grade and at 24 completed first degree; the mid-point between 15 and 24 being 19.5 should probably mark a person`s first year at university or institute of higher learning. Therefore, HIV/AIDS seems to pose threats not only to health, but also to young people`s education (Kelly 2000, Otaala 2000, Chilisa, Bennell and Hyde 2001), and other aspects of their life which makes necessary a study like this that is aimed at on one hand contributing to minimising the disease`s impacts on HIV-positive students, and on the other relieving students in limbo (students who do not yet know their HIV status) students. In line with attending this compelling need, this study is not on HIV/AIDS itself, but on exploring conceptions of HIV-positive university students from two diverse countries –Finland and Nigeria. The two countries differ greatly; table one below points out some of their differences. However, the two countries somehow came close in a given rating; while despite the adverse poverty and many other challenges in Nigeria the citizens in 2003 were ranked as the happiest people on earth by the New Scientist (New Scientist 2003), similarly in 2012, Finns were rated as the second (behind Australia) happiest people by OECD amongst her 34 member states plus Russia and Brazil; but this ranking

was based on 'Better Life Initiative' survey of 24 indicators in 11 categories[1] (OECD 2012, Reinhardt 2012).

**Table 1.** Differences between Finland and Nigeria

| No. | Finland | Nigeria |
|---|---|---|
| 1 | Population: 5.4 million | Population: Over 150 million |
| 2 | Among the least corrupt | Among the most corrupt |
| 3 | Geographical locations: polar region | Geographical locations: Tropical zone |
| 4 | Skin colour: white | Skin colour: black |
| 5 | Languages: 2 main languages | Languages: over 300 languages |
| 6 | Culture: monoculture | Culture: multicultural |
| 7 | Ethnicity: homogeneous | Ethnicity: heterogeneous |
| 8 | Life styles: circularly based | Life styles: somewhat religiously based |
| 9 | Social relationships: somewhat reserved | Social relationships: open |
| 10 | Communication-wise: mostly introverts | Communication-wise: mostly extroverts |
| 11 | Education: free, compulsory, & high quality | Education: expensive, by choice, & low quality |
| 12 | Literacy: 100% | Literacy: 61.3%[2] |
| 13 | Technology: advanced | Technology: far behind |
| 14 | Development-wise: developed country | Development-wise: developing country |
| 15 | Electrical power supply: constant | Electrical power supply: epileptic |
| 16 | Internet access: broad access | Internet access: limited access |
| 17 | Gender and social equality: equal | Gender and social equality: wide gap |
| 18 | Financial equity: little gap between the have &the have not | Financial equity: wide gap between the have & the have not |
| 19 | HIV/AIDS populations & proportions: 2600, aged 15–24: 0.1% (male 0.1%, female <0.1%) | HIV/AIDS populations & proportions: 3,300,000, aged 15–24: 1.6% (male 0.8%, female 2.3%) (UNAIDS/WHO 2008, UNAIDS 2011) |

Furthermore, as shown in table one above, the two countries also differ in HIV/AIDS populations and proportions. The overall number of people living with HIV/AIDS (PLWHA) in Finland and Nigeria are 2600 and 3,300,000 respectively (UNAIDS 2011), and based on the UNAIDS/WHO (2008) global HIV/AIDS epidemiological fact sheet[3], HIV prevalence amongst young Finns and Nigerians (aged 15–24) are 0.1% (male 0.1%, female <0.1%), and 1.6% (male 0.8%, female 2.3%) respectively; a statistics which show that the prevalence gap amongst the youngsters in the two countries is very wide. But besides the numbers, one undisputable fact is that being diagnosed HIV-positive is not the dream of many because that may forever twist an individual's entire life. So this study looking beyond HIV/AIDS speculations and generalised views, focuses on what living with the disease mean to HIV-positive student based on

[1] The 11 categories are – Housing, Income, Jobs, Community, Education, Environment, Civic Engagement, Health, Life Satisfaction, Safety, and Work-Life Balance
[2] https://www.cia.gov/library/publications/the-world-factbook/fields/2103.html
[3] http://apps.who.int/GlobalAtlas/predefinedReports/EFS2008/index.asp

their understandings of it and its influence on their health, education, productivity, and future goals. The study also showed interested in how the disease had transformed or reformed the participants.

## 1.2 The usage of the key word – 'conception'

One of the key word used in this study is 'conception'. Although conception is a popular word in phenomenographic studies, its interpretations could be broad and confusing, so to prevent readers from getting confused, I see it essential to explain the context under which the word or its phrase (conceptions of HIV/AIDS) is used in this study. Conception is used here as an umbrella word which encompasses 'conceptual thoughts and immediate experiences' as Marton (1986) suggests. The former is focused on the knowledge and understandings of the participants primarily based on what they have learned about the disease[4], while the later is primarily based on the direct experiences of the participants with the disease. So the two aspects of conception were explored in this study in order to capture the whole picture of the participants` ideas and reflective thinking on the meanings of living with HIV/AIDS based on acquired knowledge and individuals` direct experiences with the disease. The next section further elaborates on the background of this study including introductory insight on what it mean to be diagnosed HIV-positive at a promising age.

## 1.3 Research background

The works of a researcher to a large extent reveals who he/ she is, so – who is this researcher, and why did he chose to do this study. Well, describing who I am may be somewhat difficult, but to put it simple; I am a health conscious person with zeal for exploring related knowledge and sharing them with others. This explains why beside having a bachelor degree background in 'Public Health Education', my first master's degree[5] thesis was written on *'The Anti-smoking Health Educators` Conceptions on 'Smoke-free Finland 2040 (Savuton Suomi 2040)' Goal'*, notwithstanding that the studies were on *'Education and Globalisation'*. Similarly, this doctoral study on *'Education'* is investigating the conceptions of HIV-positive Finnish and Nigerian university students.

The drive to do this study is somewhat influenced by my past ill health experiences and an outstanding academic challenge. Starting with the former, I repeatedly suffered severe malaria fever during my childhood, and according to my parents` narratives I almost died. This was probably due to my AA genotype which made me more prone to malaria (Fleming et al. 1979, López et al. 2010). Although the frequent occurrence of the illness continued during my adolescence, it significantly reduced during my early adulthood, and now I hardly experience malaria attack. But during my early adulthood, I developed peptic

[4] Although that in a way is experience, but being primarily mental experience it is separately explored as a part of conception on the disease

[5] However, my second master`s degree is on Public Health Nutrition, and my research work therein is on Metabolic Syndrome.

ulcer which I have continued to manage till date. On the later, my academic pursuit was somehow challenged during my senior secondary education, and at some point it led to my drop-out for almost a decade. Nevertheless, I was compelled to return to school because nothing outside the academic world seemed mentally challenging enough.

So being an individual who has passed through severe ill health, and was also seriously challenged academically, I have developed strong concern for individuals (especially students) who are chronically ill, and also those whose academic pursuits are challenged in one way or another. As such, it is of great personal interest, development, and consolation to investigate the plights of fellow students who are exposed to a challenging illness which can even lead to dropping-out of school. So, I see this as a great privilege to make in-puts in informing and transforming students at health crossroads, and this has a strong stake in the motivation for this study. But beside the personal encounters, I particularly chose to investigate university students living with such a debilitating disease whose name many are not comfortable with for a particular purpose.

### 1.3.1 Research motivation

The desire to do a study like this has lingered for some time; the intrigue started in the early 1990s when to my astonishment a Nigerian lady (probably in her 20s) in a television interview expressed her loss of interest for a scholarship in a US university. As she expressed it, gaining the admission had been the dream of her life which she strongly held on to and worked hard for. However, she abandoned the dream shortly after it came through. Amazingly her reason was that she had just been diagnosed HIV-positive, and as such sees no need to continue her education since she was going to die soon. Although as at that time HIV/AIDS was seen only as a terminal disease or death sentence (Baumgartner 2007), but it was unimaginable to hear that someone will forfeit a university education for testing HIV-positive, and unfortunately according to the narrative her dreams for a bright future was also twisted by the positive diagnosis.

There might have been other hidden factors behind her unfortunate decision, and the motivation to even declare it on air; for instance, recently as reflected in the literature review, I discovered that the US travel ban on PLWHA was lifted just few years ago (CDC 2009). So probably HIV screening was part of the admission requirements, and the ban might have contributed to her unfortunate decision. Nevertheless, the image registered in my mind for about two decades is primarily what triggered the urge to do an in-depth exploration of the influences of HIV/AIDS on university students. In addition, my knowledge on the increasing number of PLWHA amongst university school-age young people made the urge even more compelling, and the zeal has continually been revived by my knowledge of specific school-age individuals who are said to have died of HIV/AIDS since early 2000s.

For example, on a given day in the early 2000s while I and two other friends were driving somewhere within Lagos Nigeria, we suddenly saw a crowd gathered, and out of curiosity we decided to find out the reason for the assembly. To our surprise, the crowd was attracted by a homeless young man who was un-

consciously lying by the roadside and had messed-up his whole body. Seeing that no one was willing to help him, we suspended our mission, cleaned him up, and carried him to a nearby general hospital. But unfortunately the next morning we were told that he died over the night of Tuberculosis (TB) and AIDS. While I was still nursing the shock of such sudden death news, a friend requested that I accompany her to a sick school friend. Upon arrival, we met a speechless young lady in her early 20s almost reduced to skeleton. Based on her mother`s narrative, she was brought home from a hospital after a long in-patient treatment could not improvement her health. Unfortunately, few months later we got the news that she has also died. The rumour that followed was that she died of HIV/AIDS. Shortly after that, a school-age relative of another friend died. About six months later, two other individuals I know also died, and the rumour which also followed the death of each was HIV/AIDS. But beyond the above incidents and curiosity to acquire better understanding on HIV/AIDS, as hinted earlier, I chose to do this study because haven been challenged academically and health-wise, my sense of empathy for students with this serious health condition could not be appeased with any other thing except doing a study which might contribute to the mitigation of the impacts of the debilitating disease on them.

### 1.3.2 Research objectives

Studies in education are often focused on ‘what’ the students are taught and ‘how’ they are taught, and only on seldom occasions in-depth attention is paid to ‘who’ is taught. The trend has continued notwithstanding the well-established fact that students` backgrounds, personalities, identities, and so forth influence their academic successes or failures, and living with HIV/AIDS is not an exception. Unfortunately only a little is known about the effects of this acquired and undesired identity on the HIV-positive tertiary students because studies on how and to what extent the disease affects students in institutes of higher learning have only been scratched on the surface. As such, the needs of HIV-positive students in such institutions are often ignore; and hiding from the burden of shame which has always followed the disease, such students find it difficult to stand up for their rights which also makes investigating their plights essential.

But what exactly do I want to achieve with this study? While the plights of PLWHA seem pitiful because living with a devastating and undesirable constant reminder of inevitable death is worrisome, one of the greatest challenges with the disease is that there are still many unknowns mostly because meanings of the disease are clustered here and there contributing to the high subjectivity of HIV/AIDS conceptions. So in view of this challenge, this study is aimed at bringing together the clustered meanings of living with HIV/AIDS in an attempt to objectify its conceptual subjectivity. Then going by the fact that the theories of individuals suffering a given illness are influenced by among other factors their bodily experiences (Anderson and Spencer 2002), and also in view of the need to provide suitable school interventions tailored towards checking the challenges HIV/AIDS has on university education; there seems to be no better way out than the exploration of the impacts of the disease on HIV-positive students

from at least two diverse countries to suggest (based on their thoughts and experiences) viable and adequate measures for mitigating the negative impacts of the disease on students. The study is also aimed at providing other individuals better understandings of the disease especially the students in limbo who are also in need of making psychological and physical adjustments.

Furthermore, apart from the fact that no earlier studies seem to have directly explored the conceptions of HIV-positive university students, the exploration seems necessary because unlike the above narrative on a HIV-positive Nigerian lady, the participants have scaled through university enrolment wherein she failed. By comparing the conceptions of the HIV-positive Finnish and Nigerian students from broad perspective, my aim is also to capture the understandings of students living with the disease on HIV/AIDS, and how the disease has been influencing their education, health (emotional/ mental, physical, and social), productivity, and future goals. Then in view of the fact that the negative impacts of the disease are well established, the study from the outcomes stretches beyond the negative conceptions of the participants to identify and elaborate on the therein benefits of living with the disease (especially the positive transformations living with the disease have made in the participants) and use them as a platform for drawing attention of all to healthful living. In addition, the study also aimed for providing opportunities for HIV-positive students in both countries to learn from each other`s experiences.

### 1.3.3 Research questions

In order to adequately do the proposed work, and attain above research goals, this study is approached through the following four research questions:

1. What knowledge and understandings do the Finnish and Nigerian HIV-positive University students have on the disease?
2. In what ways has the disease affected their health (emotional/ mental health, physical health, and social health), education, productivity, and future goals?
3. What transformations and/ or reformations has the disease had/ made on the participants?
4. What are the differences and similarities in the Finnish and Nigerian participants` conceptions of the disease?

### 1.3.4 Significance and scope of study

Scholarly this study seems significant because it will contribute to checking one of the rising students` challenges with academic pursuits, and since the field of study has only been scratched on the surface, I envisage that the study outcomes will be of academic and social significant. The study is also somewhat unique because unlike the earlier ones, it empirically analysed the conceptions of HIV-positive students. Furthermore, the research findings may among other importance reduce the stresses of HIV-positive students, and also that of other concerned individuals – especially the students in limbo. The study may also

make HIV screening more appealing than it is at present. Then as a study which investigates the plights of a disadvantaged group from a cross-national perspective, it not only outlined but also compared the disease`s mitigation mechanisms and the benefits of living with the disease.

As stated earlier, it is worth noting that this study is not on HIV/AIDS itself, but on the meanings ascribed to the disease by HIV-positive students. As such, the study did not explore attitudes (feelings and behaviour) towards HIV/AIDS but rather sought for conceptions primarily based on thoughts and experiences with the disease. Also sexual behaviours and other HIV causative factors were not explored, but rather the experiences of students already infected with the disease. Statistics on PLWHA was also not the primary focus of this study, but rather the meanings of living with the disease. More also this study did not search for, or lay emphasis on HIV prevention and control mechanisms, but explored how the quality of life of HIV-positive students could be improved through effective psychosocial interventions which will also positively change behaviours of victims, and also reduce stigmatisation and discrimination from others. Then since it is the views of HIV-positive students that is being studied, hence '*conceptions on HIV/AIDS*' as designated in this work are explained from individual and collective meanings attributed to the disease by the participants based on their understandings and experiences.

### 1.3.5 Research audience

Above every other persons or group of persons, this study has benefited me most. This is because when I started this study I knew only but little about HIV/AIDS, but now I have come to know so much about the disease. However, this study is primarily aimed at two main group of audience – the HIV-positive university students and the students in limbo; and due to the presumed limited medical/ health knowledge of many that fall within the targeted audience, my logical arguments have been presented in simple manners and straight to the point.

For through reading the understandings and experiences explored here, the HIV-positive students in Finland, Nigeria, and other part of the globe will know the conceptions of their fellows which may in one way or another broader their knowledge and understandings of the disease; thus learn how to further mitigate its impacts on them. The study may also increase the HIV/AIDS knowledge and awareness of their friends and family members which may in return improve attitudes toward them. Furthermore, in line with Serlo (2008) which reveals that students` negative feelings towards HIV/AIDS and the PLWHA are often based on fear, the students in limbo who are often frightened to their marrows at each time HIV/AIDS is mentioned may through reading this study have some of their fears and worries (due to unknowns) eliminated because detailed HIV/AIDS pictures have been painted by those already wearing the shoe and know where it pinches most. As such, their motivation for voluntary HIV screening may improve.

Universities` student affairs department could also be part of my audience because reading the study may contribute to improving their services and there-

by contribute to making school environment more HIV/AIDS friendly. The study may also contribute to enhancing the programmes of Ministry of Health and Education or pushing for change in HIV/AIDS policies. HIV/AIDS Organisations too may find in the study outcomes ideas for better tailoring their services toward improving the quality of life of their subjects. Furthermore, fellow scholars may also use the findings of this study to improve their understandings of HIV/AIDS. Then beside students, other members of the public who need to improve their knowledge and quality of life through healthful living may also benefit from this study which used its findings as a platform to promote positive and healthy lifestyles.

This is a five chapter study; and as demonstrated so far, this chapter has rightly introduced the research aims and research questions which guided the context of this study. The next chapter reviews literature and as such gives the theoretical framework for the study. In addition to the reviews on HIV/AIDS, the chapter also reflects a little bit on education, health education, health science, preventive/ lifestyle medicine, psychophysiology, and so forth. Chapter three give insight on the methods and approaches used in collecting and analysing the empirical data with step-by-step description of the entire process followed. In Chapter four, the outcomes of the analysis are described, compared, examined, and mapped in ways readers can easily understand. It also provides detail accounts of what the study discovered. Finally, the chapter five discusses the key findings of the study, outlines their main implications, and drew conclusion.

# 2 LITERATURE REVIEW

In this chapter, literatures are reviewed under three sections: education, mainstream views on HIV/AIDS, and education for healthful living' all of which form the theoretical framework for the empirical data analysis. The first section begin by exploring education from general perspective; and later narrowed to essence of it and highlighted factors which affect students` academic pursuits. The second section shows a comprehensive review of contemporary HIV/AIDS` mainstream views relevant to this study. Finally, the third section briefly reviews 'education for healthful living' as an essential part of mitigating the impacts of HIV/AIDS. The brief exploration of the principles was not part of the initial plan, but that was added after the empirical data analysis revealed that the participants (especially the Nigerians) instead of being the pitiable individuals whose numbered days are full of sorrow; they showed that living with the disease motivates healthful living which has even made them healthier than they were before HIV-positive diagnosis.

## 2.1 Education

The importance of education can never be overemphasized; it has greatly contributed to transforming the world into what it is today. There are even believe that education will contribute to ushering the world into 'utopia', an ideal society desired now (when degenerations and increased vices are becoming rampant) more than ever. Narrowing the importance of education to individuals, Kelly (2000) argues that, the aim of investing in education is to prepare individuals to live harmoniously, constructively and happily as members of the local, national and global community. The former Finnish president (Tarja Halonen) in a recent Yle television interview said if she is given the opportunity to admonish the Finnish society in three words, her choicest words will be: educate! educate!! educate!!! Although the cost of education everywhere in the world is expensive[6], however, illiteracy costs even much more; for those who have distanced themselves from acquiring education have continued to pay dearly for it in one way or another. Perhaps this is one of the main reasons why there are today many literates. But though there never existed this many scholars and literates in the world`s history as in this generation, nevertheless, illiteracy is still rampant.

### 2.1.1 Essence of education

Nelson Mandela argues that education is the most powerful weapon for making transformative changes (Bi-Botti 2009). Finland is a good example of the power

[6] Even in Finland where no tuition is paid, the government spends a lot of money on education, and besides its financial costs students put in a lot of time, mental task, commitment, physical energy, and so forth into education.

of education to positively transform a society; about a century ago she was just like any other developing nation-state, but through her education reforms especially in the early 1970s (Sahlberg 2011), she has emerged economically buoyant and her education style has become one of the world`s most enviable. Similarly, China, India and other emerging nation-states could to a large extent credit their successes to the education of their human resources, because education does not only benefit individual students and their immediate families, but also their nation-states. As such, education should be recognised for what it is – 'the life blood of every nation-state'.

In the light of all these facts, it seems education is the greatest empowerment every child deserve; so instead of being seen as an option, it should be taken as a necessity because it enable children to become capable, creative, skilful, productive, and equipped to solve day-to-day problems (UN 1987, WHO 2002)[7]. In agreement with this line of thought, during my primary education, we use to recite a poem in my mother tongue (Igbo) that reads:

akwukwo na atouto, onarahu na nmuta,
onye nwere nkasi obi, ogamuta akwukwo,
oburu na nnegi na nnagi nwere ego o,
igamuta akwukwo, achirim ochi hahaha ewo!

In English, it means: *"Education is interesting, it is difficult to acquire, but whoever has patience will acquire it, and if your parents are economically buoyant, you will acquire it, oh what an endless laughter"!*

But beside primary and secondary education, every individual also deserve the equal right to acquire knowledge through the four walls of tertiary institutions the most popular of which is university. During my bachelor degree, a lecturer in library science class once defined university as "buildings surrounding a library". Although the definition seems somewhat appealing, nevertheless, the most important part of the university community (students) is not dully mentioned. For a university may somehow survive without some parts of her faculties except for one – the students. After all, one of the most important goal of a university is to produce skilled workers, so unlike in the primary and secondary schools where existing paradigms and theories are often passed on to students, tertiary institutions give students the opportunity to critically analyse and question existing paradigms and theories, and possibly come up with theirs. So seeing university in the context of what has been said so far, it may be more appropriate to define it as 'a conducive environment where students` thinking faculties are developed for positive transformation of academic institutions and societies at large'. So everyone should be given the equal right to pass through her walls in order to meaningfully contribute to bettering the world, but unfortunately many are denied the opportunity for different reasons.

[7] Robinson (2011) argues that the predominant academic laden education system designed to meet immediate market demands is actually educating children out of creativity.

### 2.1.2 Factors influencing students` studies

Many factors influence students` academic pursuits and possibly drop-outs, but the factors vary depending on the setting. In Finland, although even since Finland`s high PISA[8] (Programme for International Student Assessment) scores in the early 2000s (Simola 2005), there have been increase in foreign delegates flocking into Finland (European Commission 2014), many of whom are on 'education tourism' and came just to ask – what is your secret?[9] Nevertheless, Finnish education has her challenges; for instance, in view of the statistics which suggest that without proper education or professional trainings, Finnish youth are more likely to end up unemployed, there is now a proposed plan championed by the minister of Education and Culture (Krista Kiuru) to extend compulsory education by a year (Yle August 2013a).

Then in Nigeria, though there are many highly educated individuals, illiteracy is rampant chiefly due to drop-out often propelled by poor academic performance. Generally, Nigerian education is overwhelming challenged by poor funding, corruption, lack of study facilities, exam malpractices, poor quality teachers, regular strike, occultism, and so forth. But despite the fact that there is a wide gap between school drop-out in Finland and in Nigeria, nevertheless most criminal activities and unhealthy habits in Finland are often attributed to illiteracy (Koskinen, Aromaa, Huttunen and Teperi 2006) not withstanding that every child in Finland is under obligation to attend school till the 9th grade. According to a researcher at Jyväskylä University's department of teacher education (Sari Sulkunen), one in every ten Finns is illiterate (Yle July 2011a). This is probably because learning how to read and write plus other knowledge acquired till 9th grade are not enough to give individuals the adequate literacy to live harmoniously, constructively and happily as members of the local, national and global community (Kelly 2000). Although the main causes of school drop-out in Finland have not been established, it is however the single largest common risk factor in crime among young adults (Yle February 2011).

But, though many factors challenge students` academic pursuits, one of the factors which seems universal is being diagnosed with HIV/AIDS; a disease whose emergence is one of the ugliest memories of the 20th century. The most regrettable thing about the disease is that it affects mostly the younger generation in whose hands lies the task of sustaining the human education and population. The next section reviews some relevant facts on the deadly disease of which more than half of those who are newly infected are 15–24 years old youngsters (UNICEF, UNAIDS and WHO 2002).

[8] An international study conducted by OECD in member and non-member countries of 15-year-old school pupils' academic performance on mathematics, science, and reading.

[9] During my master's study when we went to Paris for a study visit, the two lecturers who accompanied us were repeatedly asked by UNESCO officials – what is your secret? In addition, articles, thesis, and books have been written on Finnish education success story. Even movies and numerous presentations on *YouTube* have continued to explore the unusual factors behind Finland`s education excellence.

## 2.2 Mainstream views on HIV/AIDS

It may not be surprising that once HIV or AIDS is mentioned; many begin to feel uncomfortable, which is why the PLWHA, their family members and friends discourse the disease almost only in secrecy. The disease is also shrouded in mystery, and since its discovery in the early 1980s, it has been the subject of fierce and unending debate, arguments and counter arguments. For instance, the first time I heard about AIDS was in the early 1980s when through the media it was broadcasted as a contagious deadly disease discovered in the U.S. which is chiefly transmitted through sexual intercourse. I was of course not bothered about it because I was only but a child with no idea of what couples do behind closed doors, nevertheless it was impossible to cover my ears from its rumour-mongering. Part of the rumour that was also being circulated by 'radios without battery'[10] is that AIDS is actually a propaganda which means *'American Idea of Discouraging Sex'*. But as the rumour was trying to gain ground in the same early 1980s, next scene that followed was media bombardments repeatedly announcing that 'AIDS is real and has reached Nigeria'. So due to the mixed information, my views on the disease for some while remained mixed until in the 1990s and 2000s when I began to see realities.

So, as in many popular phenomena, there are at least two known views on HIV/AIDS; the mainstream view which upholds that HIV is real and is the sole cause of AIDS and the view which opposes it. Although the later has generally remained unpopular over the years, nevertheless it has continued to attract more and more followers. For example, in Kalichman, Eaton and Cherry (2010) study of 266 and 77 American men and women respectively who are living with HIV/AIDS, one in every five said there is no proof that HIV causes AIDS, and the participants also reflected their believe that HIV medications do more harm than good. Even the researchers of the study demonstrated that their participants who see HIV/AIDS as a hoax have been influenced by AIDS denialism.

Nevertheless, this study is not about exploring the disease itself but about finding HIV/AIDS understandings and lived experiences within two groups, so the knowledge on HIV/AIDS presented in this section are only the mainstream ones. HIV/AIDS` conceptions are highly subjective, and one of the goals of this study is to contribute to objectifying views on the disease. Although a more accurate conceptions on the meanings of HIV/AIDS and that of living with it are better derived from PLWHA as shown in the empirical data analysis outcomes in chapter four, this section reviews what we already know about the disease based on existing literatures.

In brief, the HIV/AIDS` mainstream understandings reviewed in this section begins with separately describing the meanings of HIV and AIDS, how the disease is transmitted and the factors which influences its spread. The next is brief exploration of knowledge on how HIV progresses into AIDS, and then what living with the disease is perceived to mean in Finland and in Nigeria including

[10] Individual who circulate news they are not sure about

how the media`s broadcast on HIV/AIDS has helped in creating the disease`s awareness and also somehow worsened the conditions of PLWHA. Furthermore, the impacts of HIV/AIDS on health is reviewed; examining the disease`s impacts on physical health and productivity, mental health, and on emotional and social health. Views on the importance of discovering positive status early is also looked into after which was examined the challenges with disclosing HIV-positive status. Then the main HIV/AIDS social health problem – 'stigma and discrimination' is separately reviewed. The next review is concerned with the impacts of the disease on education. Impacts on primary, secondary, and tertiary education is also separately explored. Afterward is the review on the disease`s impacts on future goals. Subsequently, ways in which the disease has affected the Finnish and Nigerian societies is also reviewed. Then the next was the reviewing of the existing knowledge on HIV/AIDS vaccination. treatments, and cure, after which followed the mitigating modalities for HIV/AIDS impacts which include sex education empowerment, plus self and social support for coping with the disease.

### 2.2.1 The meanings of HIV and AIDS

Starting with the later, AIDS is a known acronym meaning 'Acquired Immune Deficiency Syndrome', which is often used to illustrate a conglomerate of signs and symptoms arising from the development of opportunistic infections (Mandell, Bennett and Dolan 2010). The human body like that of other animals is naturally fortified with disease or foreign body fighters known as 'immune system'. Normally they work so perfectly that in many occasions their tasks of disease eradication go unnoticed. But a person is said to be having AIDS when his/her viral load is high and CD4 T cell Lymphocyte count is less than 200/ul (Mandell, Bennett and Dolan 2010) a point the individual cannot adequately fight diseases on his/her own. A further illustration of the meanings imbedded in the four word acronym is as follow:

A – Acquired: Something that is obtained or received – Foreign body
I – Immune: Resistance to disease – Disease fighters in the body
D – Deficiency: Failure or lacking – Inability to fight diseases
S – Syndrome: Group of symptoms – Disease reflecting a particular set of symptoms

So in view of the above facts, AIDS can simply be defined as "a disease of the human immune system that is characterised cytologically especially by reduction in the numbers of CD4-bearing helper T cells... thereby rendering the subject highly vulnerable to life-threatening conditions" (Merriam-Webster 2014a).

AIDS first emerged in America in the early 1980s when the American Center for Disease Control (CDC) published in MMWR (1981) the unusual cluster of Pneumocystis Carinii Pneumonia (PCP) in five gay men from Los Angeles suffering from Pneumonia. Subsequently in 1983 Human Immunodeficiency Virus (HIV) was named as the disease which causes AIDS. The acronym HIV represents the following:

H – Human: The human race as represented by men and women
I – Immunodeficiency: lacking of defence system
V- Virus: Any of a large group of submicroscopic infective agents... that are capable of growth and multiplication only in living cells, and that cause various important diseases in humans, lower animals, or plants (Merriam-Webster 2014b).

Although HIV was named in 1983 as the virus that causes AIDS, its origin remains shrouded in mystery, and it has attracted many theories and counter theories. As well, while the mainstream literatures on the disease hardly talk about its origin, the media sometimes gives conflicting information about it, and it seems many hold the believe that the disease existed long before its discovery.

#### 2.2.1.1 HIV transmission

HIV is found in the human body fluids (WHO 2005) which include: human blood, virginal fluid, semen, breast milk, tears, and so forth. As such, the virus may be transmitted through the direct contact of the body fluids of an infected person with the mucus membrane (eyes, nose, mouth and genitals) of another person. It is generally believed that the most common means of contracting HIV is unprotected sex. So individuals – especially young people are advised to abstain from sexual relationship before marriage, while the married are encouraged to remain faithful to their partners. But for the singles who are sexually active and cannot control their passion; they are often advised to constantly use condom, but there is no assurance that condoms guarantee 100% protection.

#### 2.2.1.2 Factors influencing the spread of HIV

Two of the main factors believed to be responsible for the wide spread of HIV are lack of clear knowledge and lack of will power. Women and girls often have less information about HIV, and also fewer resources to protect themselves (UN Women 2011a). Generally, young women seem to have less information about HIV/AIDS than their male counterparts. For instance, only about one in every five married women in Bangladesh have heard about AIDS, while in Sudan not more than 5% of women know that condom use could prevent HIV infection (UN Women 2011b). In some parts of the world, rape is instrumental to the spread of HIV and other STDs. This is because probably rape often results in abrasion and bleeding which makes HIV transmission easier.

Unfortunately, while some will not want to share a seat with PLWHA, many still carelessly indulge in the acts which encourage the disease`s wild fire like spread. Although sexual contacts often accompany migration and tourism (Clarke 2004), but it is actually the failure of many to accept that they are among the high-risk group, and their lack of commitment to safe sex that mostly fuels the spread of HIV (Durojaiye 2011). According to Holmström (2002) destitute are often the most vulnerable. In some cultures especially in the developing countries, coerced sex is often inevitable, and this makes women more vulnerable to HIV infection because in such environment, women are unable to

negotiate safe sex or refuse unwanted ones (UN Women 2011b). Maman et al. (2001) study on 'HIV and Partner Violence' in Tanzania revealed that women greatly suffer violence from their male partners. Conflicts and wars in addition facilitate the spread of HIV, which leads to women often being purposeful infected (Rehn and Sirleaf 2002). Alcohol consumption among other social norms often hinders efforts on curbing the spread of HIV. NordPol (2007) revealed that a large number of those who tested positive to HIV after 2002 still indulge in unprotected sex under the influence of alcohol and drugs.

#### 2.2.1.3 HIV progression into AIDS

HIV and AIDS are often used interchangeably or together, however the two are not the same. As illustrated earlier, AIDS is popularly known as the most advanced stage of HIV infection. It is believed by many that it takes about 10–15 years for an HIV-infected person to develop AIDS, but in some individuals it takes even more. Antiretroviral drugs may even further help in slowing down the progression of HIV into AIDS (WHO 2010a). While people living with AIDS are often assumed to be having HIV too, those who have HIV in most cases may not necessarily have AIDS. One is said to be having AIDS when his/her CD4+ lymphocyte count falls far below normal (AIDS Gov 2010, CDC 2014). This extremely low immunity means that the person is not healthy enough to fight intruding diseases known as 'opportunistic infections'.

It is believed that when a person contracts HIV, the viral load of the person will continue to multiple as the virus attack and destroy the person`s immune cells through using them as breeding grounds. This process starts with 'primary HIV infection' and continues until it graduates into what the mainstream media often refer to as 'full blown AIDS'. It is also believed that if the disease is not well managed, it may destroy so many immune cells to the point that the individual will not be able to fight invading opportunistic diseases which may eventually kill the individual. In view of the above explanations, HIV is generally said to had progressed into AIDS when the person`s immunity is very low, and the viral load presence in his/ her body is high (Weiss 1993).

### 2.2.2 Conceptions on living with HIV/AIDS

HIV/AIDS conceptions seem to vary based on gender, race, age, literacy, environment, and so forth. Even by status, PLWHA`s views on the disease differ from the views of those who are negative, or better still those who have not confirmed their status. The most common conception[11] on HIV/AIDS has remained that it is a contagious death sentence. This conception is mostly due to lack of satisfactory insight on what HIV/AIDS really is, which may be why the conception seems to be on the decline. In Anderson and Spencer (2002)[12] phe-

[11] The usage of the term 'conceptions' was borrowed from phenomengraphy, so its usage is in the context of phenomenography

[12] Due to great similarities between the outcome of Anderson & Spencer`s (2002) phenomenological study of cognitive representation of AIDS and this study, references were frequently made from it.

nomenological study of cognitive representation of AIDS, the disease is conceptualised as: inescapable death, dreaded bodily destroyer, life devourer, holding a wildcat, just a disease, and so forth. Similarly, in Awa and Yamashita (2008) study of persons' experience of HIV/AIDS in Japan, five pattern of evolving stages emerged which are: self-conscious of own sexual orientation, chaos, stagnation, turning point, and gaining a new identity.

Generally, testing positive to HIV/AIDS is often seen as receiving emblem of death. As tuberculosis and cancer were mythologized in the 19th and 20th century respectively, towards the end of the 20th century AIDS was mythologized as the punishment for sexual or social deviance (Clarke 2004). Although HIV/AIDS is a deadly disease, but in many occasions it is often over exaggerated. The disease is often linked to immorality and promiscuous sex which makes the disease even more unacceptable in many societies. Many for the lack of knowledge or limited of it go extra miles in avoiding PLWHA in order not to get infected. The deadly views of the disease somehow differ from one person to another and from one nation to another. In Anderson and Spencer (2002), some participants envisioned AIDS as people who are reduced to skin and bones, extremely weak, in pain, losing their minds, and lying in bed waiting for the end. One of the participants (a woman) even went as far as picturing AIDS as a 'skeleton crying'. While another in expressing her devastation pictured AIDS as *"Pain from head to toe, no hair, 75 pounds, can't move, can't eat, lonely and scared. Family loving you and you can't love them back"*. Yet another (a 48 year old man) in picturing it as a life devourer says, *"I feel I have no life. It has change my whole perspective"* (Anderson and Spencer 2002, 1344).

Often what people fear most is the stage of the disease called – AIDS. For many preventing HIV from becoming AIDS (or at least delaying it) is a good reason to discover ones positive status early (Porter, Wall and Evans 1993, WHO 2010b), because with HIV one still has the chance to fight the disease but once AIDS begin to appear in one`s record, the person would have bought a ticket to the grave (Anderson and Spencer 2002). But some make AIDS sound better by painting it as a chronic disease like cancer or diabetes which only requires punctual and regular use of medications. With this mindset, another participant in Anderson and Spencer (2002) who`s conceptions has changed over the years says: *"At first I thought I was going to be all messed up, all dried up and looking weird and stuff like that, but I don't think of those things anymore. I just keep living life"* (Anderson and Spencer 2002, 1348). Other studies have also found that PLWHA often use the image of chronic disease to minimise the weight of AIDS (WHO 2008). This increasing ray of hope is probably because with modern medicine, the impacts of the disease are now less deadly as they use to be, and the PLWHA who have responded well to treatments now pursue careers, raise families, and live healthy (Clarke 2004). However, all is not well yet, there are still much to be done in bettering HIV/AIDS conceptions.

### 2.2.3 HIV/AIDS conceptions in Finland and Nigeria

Conceptions on HIV/AIDS somewhat differ from place to place. In the Finnish context, the primary framework for understanding AIDS is gay plague (Clarke

2004) (that is a plague primarily designed for a community whose practices are immoral). Such tagging might have been because the disease was first discovered among gays – a community which was not accepted in the Finnish society until in the 1970s. The discovery of the disease in Finland raised moral panic and debates which got to their peaks after the first reported AIDS death in the 1980s. One physician is said to have suggested in a major Finnish newspaper that 'Moses may have had a good health reason for prohibiting disease borne behaviours which includes homosexuality' (Ibid)[13]. So the rejection of the disease and the people living with it in Finland in the 1980s was exceptional. One vocal camp went as far as suggesting strong managerial response which includes quarantine. There were also talks on sending infected individuals to unused leper colonies (Clarke 2002).

However, the Finnish perceptions on HIV/AIDS got broader when heterosexuals, women, drug addicts, and migrants began to test positive to the disease. The fact of the matter is that to many Finns the disease is no more what it was in the 1980s and the epidemiological facts have after the 1980s continued show that heterosexuals are increasingly represented in the community of PLWHA in Finland (Clarke 2004). Particularly, in the 1990s the Finnish views of the disease took a drastic twist – 'the plot of African AIDS' (that is a narrative of foreign threat toward Finns). Many Finns began to believe that HIV/AIDS was primarily borne and transmitted by migrants especially after the case of one African-American (Steven Thomas) who was convicted and sentenced 14 years for deliberately spreading the disease (Clarke 2002). Nevertheless, unlike in Africa and many other parts of the world, the numbers of PLWHA in Finland remains relatively small, and as later portrayed by one of the participants of this study (in chapter four), that seems to have added to the isolation and suffering of the PLWHA in Finland.

In Nigeria where the gay community hardly exist, HIV/AIDS was never seen as a gay plague but heterosexual disease of promiscuous lifestyles. The negative conceptions on HIV/AIDS in Nigeria though not well documented, use to be as strong as death. Many Nigerians use to associate every little illness to HIV/AIDS. So in a country where putting on some weight is often seen as an evidence good living and wellbeing, and also where promiscuous sex though rejected is very popular; once an individual begins to lose weight, the rumour that often follows was that such person might have been infected with HIV/AIDS. Then to worsen the bad situation, because many in Nigeria do not practise safe sex, the fear that one might have been infected with HIV often added to the stress of sick individuals who might only be suffering from malaria – the most common illness in Nigeria (NMFS 2011).

Although I have heard and read a lot about HIV/AIDS` stigma and discrimination in Finland, I do not believe that it could be equated with that of Nigeria prior to my moving to Finland about 10 years ago. Nevertheless, my recent

[13] Original idea from Vaheri, Antti (1985 June) Rokotuksissa tarvitaan yhteiskunnan patistusta. [Vaccinations need urging by society] (interview) Helsingin Sanomat.

observation whilst collecting data for this study shows that the tie is changing[14]. As stated in the motivation for this study in chapter one, the strong negative view of the disease in Nigeria probably played a large role in the Nigerian HIV-positive young woman refusal of US University scholarship, while as in Finland that might not have happened. Of course, unlike in Finland, it seems it is the Nigerian societal structure which makes the discrimination of PLWHA even worse. For instance, unlike in Finland where individuals somewhat live independently, in Nigeria family ties are strong, for most individuals no matter how hard they try, they will hardly isolate themselves; of course this has its advantages too, but in the context of being diagnosed with HIV, such strong ties may worsen the bad situation. As a way of escape, I remember in the early 2000s someone once told me that if he tests positive to HIV, he will run away from his people and relocate to where no close relatives and friends will know what actually killed him. The same is reported to be occasionally happening in South Africa (Timberg 2005).

### 2.2.4 The media: A friend or foe?

In many civilised societies, the media remain the primary source of information. But unfortunately it seems in some settings the media does not follow her ethical guidelines strictly whilst reporting on HIV/AIDS. As also demonstrated by all of my Finnish participants, it seems while reporting on PLWHA an individual`s protection is of secondary importance, which may be the reason why though the first AIDS case in Finland was confirmed in June, 1983, prior to that, the Finnish media is said to have published over 50 articles on AIDS painting deadly and fearful picture of the disease like: "*AIDS devours its victims before your very eyes AIDS*" (Clarke 2004, 222). The period was also characterised with media '*busy body'*, and journalists were constantly seen around the hospitals in search for the opportunity to take the picture of someone with AIDS (Ibid). As such, it seems the PLWHA in Finland see the media as a threat to their life, and this view may not be exclusive to Finland, while as there seems to be strong links between AIDS coverage and AIDS suicides (Aro et al. 1995).

### 2.2.5 Impacts of HIV/AIDS on health

Undoubtedly, HIV/AIDS has devastating impacts on human health. These impacts are not just on physical health, but also on mental health and social well-being in correlation with World Health Organisation (WHO) definition of health as *"a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity"* (WHO 1948). Awa and Yamashita (2008) also confirm that HIV/AIDS has physical, mental and socio-economic health implications. Perhaps this is the reason why many of the PLWHA in Nigeria and their families are getting frustrated with managing the disease (Ogunjuyigbe, Adeyemi and Obiyan 2009). Furthermore, in Vogl et al. (1999) study

[14] It seems HIV is no longer the living hell it was in the 1980s, 1990s, and early 2000s when knowing about one`s positive status hurts more than the disease itself.

of 504 patients with AIDS who were not taking protease inhibitor (PI) medications, the most prevalent symptoms found in them were worry, fatigue, sadness, and pain. So as illustrated by WHO`s definition of health, whatever affects any aspect of human life, affects health, and the sub-sections below further highlights ways HIV/AIDS affects aspects of human health.

#### 2.2.5.1 Impacts on physical health and productivity

HIV/AIDS being a deadly disease has many physical health impacts. For instance, in Anderson and Spencer (2002, 1345) some of the participants who believe that AIDS has destroyed their life expressed it this ways*: "It just took my whole life and turned it upside down. I can't do a lot of the things I used to. I lost a house because of it. Everything I worked for I lost." "Everything is different about me now. The way I look, the way I talk, the way I walk, the way I feel on a daily basis. I miss my life before, I really do. I miss it a lot. I don't think about it because it makes me sad*."

Furthermore, it has been well established that testing positive to HIV/AIDS has great effects on working life (WHO 2002), however, the earlier a person tests positive to HIV may also determine how much the disease would have affected his/her ability to work or study (NordPol 2007). In addition, living with HIV/AIDS increases sick leaves (Chilisa, Bennell and Hyde 2001), reduces productivity (FAO 1995), and affects economic output (Isaksen, Songstad and Spissoy 2002). But work discrimination is perhaps the greatest challenge for PLWHA (Clarke 2004). While some see living with the disease as a good reason not to work (Anderson and Spencer 2002), positive living and the use of medications may keep PLWHA well and productive for a long time (WHO 2010b). However, some of those who take HIV/AIDS` medications have complained of experiencing numerous side-effects. In some cases the side-effects led to profound weight loss, reduced quality of life, and missing of some doses (Douaihy and Singh 2001). The medications may also cause fatigue, depression, and chronic disability (Clarke 2004).

#### 2.2.5.2 Mental health impacts: Identity crisis

Beside falling ill and other physical health impacts, HIV/AIDS affects PLWHA mentally and otherwise. For instance, it is not all the PLWHA that are gay, immoral, prostitutes, promiscuous, drug users, and so forth (Clarke 2004), but the predominant plots of the disease which has continued to identify HIV/AIDS with attributes not shared by all PLWHA nor generally accepted in societies has continued to add to the refusal of PLWHA to identify themselves with the disease. Another reason why many of PLWHA do not want to accept its identity is that the disease has always been linked to dying, while as except for those who are psychiatrically sick it seems no one actually wants to die. Furthermore, revealing one`s HIV status to friends and loved ones has often attracted being mourned for while one is still alive and healthy, just because our societies identifies the disease with death. So as a means of avoiding discrimination, self-

stigmatisation and depression, many PLWHA have either refused to accept the disease, or do not see it as part of their everyday life (Baumgartner 2007).

Again in Anderson and Spencer (2002, 1344, 8), it was observed that some of the participants that were not thinking about AIDS gave the shortest answers like, *"I hate that word. I'm still trying to accept it, I think. Yes, I am trying to accept it". It's finally sinking in that I do have it and I'm starting to feel lousy about it.* Particularly, a 29-year-old woman who was diagnosed with HIV and AIDS nine months before she was interviewed drew a picture of a grave with delicate red and yellow flowers and wrote on the tomb stone *"RIP Devoted Sister and Daughter."* Over the grave, she drew a black cloud with the sun peeking around the edge and described it as symbolising her family's sadness at her death. Then another woman who has 4 kids aged 8 to 12 in expressing her trouble says *"It's not a disease that you would want to have because it's really bad. I know I get upset sometimes because I have it. You know you are going to die and I have kids. I really don't want to leave them. I want to see them grow up and everything. I know that's not going to happen"*. So learning that one is HIV positive on its own is depressing and may open doors for bad habits which may include alcoholism, chain smoking, and drug abuse. Thinking about the disease can also be very problematic. It may make the individual feel that the disease is much more an obstacle to living a normal life than it really is. So another participant of theirs who does not want to unnecessarily trouble himself with the disease says *"I try not to let it bother me because my viral load and everything is real low...."* (Anderson and Spencer 2002, 1345).

#### 2.2.5.3 Emotional and social health impacts

Despite the struggles with accepting one`s HIV-positive status, it is a pity that after crossing the bridge, there is yet another trouble; that is the disclosure of the positive status. This struggle is often due to the need to minimise the up-hill battles with the disease`s stigma and discrimination chiefly because many still lack clear understanding of what HIV/AIDS is because the 1980s images still hold sway. So due to these rivers to cross, testing positive to the disease often send overwhelming shock waves which are so hard to resist or managed. The shocks among other factors are facilitated by the fear of being isolated. However, it seems time can become the healer even to the point that the images, feelings, and processes of coping improve (Anderson and Spencer 2002). Nevertheless, the fact remains that solitude is an immediate and presumed future problem for PLWHA. For instance, in Finland, the biggest challenge for PLWHA is coping with loneliness (Clarke 2002). According to NordPol (2007) survey, 59% of respondents believe they are alone not withstanding that they prefer people`s company. Then coupled with that is anxiety, shame, and guilt feelings which often add to the existing burden of HIV/AIDS itself (Clarke 2004).

Furthermore, where access to food is either limited or unaffordable, the prevalence of HIV is also alarmingly high (WHO 2002). In Koopman et al. (2000) study of 'HIV-related perceived stress on coping with relationships, attachment and social support among HIV-positive persons', personal income was found to have great effect on the level of one`s HIV stress. Then a study of

144 HIV-positive individuals in Johannesburg shows that 10% have thought of committing suicide (Timberg 2005). Furthermore, Clarke (2004, 232)[15] points out that "*the first reaction to testing positive was the fear of death and the fear of stigmatization*". Stevens and Doerr (1993) outlined shock, fear, anguish, and suicidal thoughts as the first reaction to testing positive. Préau et al. (2008) study on suicide attempts among PLWH in France gave similar outcome. Then allowing time to be the healer, one participant in Anderson and Spenser (2002, 1348) who wanted to take his own life says: *"When I first found out, I wanted to kill myself and just get it over with. But now it's different. I want to live and just live out the rest of my life."* So being well informed about HIV/AIDS is essential, especially for coping with the initial shock of testing HIV-positive.

Beside challenges like income and shelter loss, being diagnosed with HIV/AIDS also destabilises relationships (Stevens and Doerr 1993). Studies also show that testing positive to the disease destroys the dream of marrying, having children, or working (Anderson and Spencer 2002). Nevertheless, the hope of raising family is not completely lost. A recent trial shows that antiretroviral therapy can reduce the chances of one infecting his/her HIV-negative partner by up to 96% (WHO 2011). However, individuals who tested positive after they have already built a family struggle hard to avoid their family from being destroyed. As shown in Anderson and Spencer (2002, 1347), one participant expressed her efforts not to infect her family members thus: *"Just being conscious of it because when you got kids and when you got family that you live with, you have to be extremely cautious. You got to realize it at all times. It has to just be stuck in your mind that you have it and don't want to share it. Even attending to one of your children's cuts"*.

#### 2.2.5.4 Importance of discovering positive status early

It is essential for individuals to find out their positive status early; that is before the disease has cause much damage. This will enable the infected individuals to take necessary steps in upholding their health, prolonging their lives, and avoiding the spread of the disease to others (WHO 2010b). In a study of 3,556 British men and women diagnosed with AIDS, 49% of them learned that they were infected with HIV just nine months or less before the diagnosis with AIDS (Porter, Wall and Evans 1993). Of course the individuals in the above study would have done more in prolonging the time their HIV status progressed into AIDS if they had discovered their positive status earlier. For many the opportunity is still open while the chances of free diagnosis in many countries remain on.

HIV screenings are chiefly carried out in hospitals, maternity clinics, sexual health clinics, needle exchange centres, medical laboratories and so forth. But in Nigeria many of the PLWHA tested HIV-positive either when they went to hospital for medical treatments or antenatal services (Ogunjuyigbe, Adeyemi and Obiyan 2009). This is probably because most Nigerians lack the culture of

[15] Originally from Koskimaa Tapio (1993). Kokemuksia HIV-positiivusuudesta ihmisen elämässä [Experiences of living an HIV-positive life] Unpublished Master's Thesis. University of Tampere, Department of Social Psychology.

voluntary HIV screening. Testing either negative or positive has advantages and disadvantages although most individuals prefer negative test result. When an individual tests negative, he/she may be motivated by the result to always live as one who wants to remain negative. But if on the other hand the individual tests positive, that person will be encouraged to live as someone who does not want to spread it. Testing positive will also encourage the individual to advance healthy lifestyles and drop unhealthy ones in order to remain healthy which prolongs life.

#### 2.2.5.5 The positive sides of being diagnosed with HIV/AIDS

It may be surprising to some that there are positive sides of being diagnosed with HIV/AIDS. To point out but few, while Fryback and Reinert (1999) show that cancer and HIV/AIDS patients who are positive about their disease reported better quality of life than before they were diagnosed with the diseases, in Anderson and Spencer (2002, 1348) one of participants who believes that there are positive side to living AIDS says, *"If I didn't have AIDS, I'd probably still be out there drinking, drugging, and hurting people. I turned my life around. I gave myself over to the Lord and Jesus Christ"*. As he expressed above, testing positive to HIV/AIDS can suddenly transform an individual and change him/her to a better person, as such positive test result in some sense is beneficial both to the infected individuals and to the societies at large. Such result also calls for health vigilance (Anderson and Spencer 2002) which is also beneficial in some sense. So, on these few premises, one may argue that it pays to at once go for HIV/AIDS screening. Nevertheless, there are many challenges with testing positive which includes disclosing one`s HIV-positive status.

#### 2.2.5.6 Challenges with disclosing HIV-positive status

Ordinarily, individuals do not like disclosing their personal information of which HIV-positive status is one. However, people tend to disclose such out of distress and expectance of some kind of benefit (Pennebaker and Beall 1986, Greenberg and Stone 1992, Derlega, Metts, Petronio and Margulis 1993, Kalichman, DiMarco, Austin, Luke and DiFonzo 2003). But most of the PLWHA who do not disclose their status simply believe that it is not other people`s business (NordPol 2007). So for a disease that is often discussed in secrecy due to shame, the disclosure may be more stress inducing than relieving (Serovich, Kimberly and Greene 1998). But on the other hand, studies show that the PLWHA who disclose their positive status demonstrate normal immune function and are less likely to frequent hospital than those who hide theirs (Pennebaker, Colder and Sharp 1990). This is simply because suppressing thoughts on difficult experience increases stress-related problem (Greenberg and Stone 1992). In general, HIV/AIDS narratives are seen by some experts as a positive mechanism for relieving the effects of the disease, and the lack of it in the Finnish society is contributing to why the disease`s humanisation is seems lacking (Clarke 2004).

Nevertheless, PLWHA usually hide their positive status as a survival strategy because many societies still see HIV/AIDS as a fearful, deadly, and immorality related disease specifically made for deviants, and the lack of personal narratives is generally not helping the situation. For instance only 3/400 of 'Body Positive' members in Finland are willing to give interview with names and faces (Clarke 2004). The study of 144 PLWH in Johannesburg similarly shows that 38% of the participants have not told even their family members, while 21% have also not told their sexual partners (Timberg 2005). This is probably because the disclosure of positive status to family members may lead to behavioural change which may increase the challenges of the PLWH. However, counselling the family members shows remarkable decrease of negative behaviours (Honarvar 2010), nevertheless, the initial views of the family members seem to play great roles in determining their reaction to positive result disclosures.

There are three major reactions which may follow HIV-positive status disclosure namely: supportive, hostile, or ambivalent reaction. The contemplation on any or all of them often influences the decision to disclose or not. Furthermore, Serovich, Kimberly and Greene (1998) study on 'perceived family members reaction to women`s disclosure of HIV-positive information' outlined six reaction which are: intellectual, physical, spiritual, relational, instrumental, and emotional reactions. Kimberly, Serovich and Greene (1995) on the other hand outlined six processes a person passes through before deciding to disclose HIV/AIDS status, which are: adjusting to the diagnosis, evaluating personal disclosure skills, taking inventory of whom to tell, evaluating potential recipients' circumstances, anticipating reactions of the recipient, and having a motivation for disclosing. But despite its difficulties, disclosing HIV-positive status to friends and family members is sometimes a source of strength (Clarke 2004)[16]. However, many find it easier to disclose to friends than to their family members, but disclosing to employers and colleagues is the last choice for many (NordPol 2007) probably because workplace discrimination is assumed to be the most difficult to bear.

#### 2.2.5.7 HIV/AIDS stigma and discrimination

Many studies have proven that HIV/AIDS is highly discriminated and stigmatised, and this explains why about 50% of PLWH do not know their HIV-positive status (UNAIDS 2012), and seem to have improved because it used to be 9 out of 10 people (UNICEF, UNAIDS and WHO 2002). In 1987 Jonathan Mann – a former director of the WHO Global Programme on AIDS, identified HIV/AIDS epidemic with three phases namely: 'the epidemic of HIV, the epidemic of AIDS, and the epidemic of stigma, discrimination, and denial' (Parker and Aggleton 2002). According to UNAIDS (2004) the discrimination PLWHA face are numerous. For instance, more than 50% of Nigerians say they cannot shake hand, hug or share the same toilet with PLWHA (Ogunjuyigbe, Adeyemi

[16] Originally from Koskimaa, Tapio (1993, 64). Kokemuksia HIV-positiivisuudesta ihmisen elämässä. [Experiences of living an HIV-positive life] Unpublished master`s thesis. University of Tampere, Department of Caring Sciences.

and Obiyan 2009). 60% of women in Zambia opt out of treatment due to fears of violence and abandonment resulting from the disclosure of their HIV-positive status (Fleischman 2005, UN Women 2011b). A HIV-positive woman (Gugu Dhlamini) was stoned to death in 1998 by men in her community in South Africa after she had declared her HIV-positive status on radio and television (UN 2007). Still in South Africa, another woman was also killed outside Cape Town in 2003 after she told a group of men who gang-raped her that she has HIV (Timberg 2005). But beyond the rampant stigma and discrimination (Naidoo et al. (2007), PLWHA are often blamed for the spread of the disease (Ogunjuyigbe, Adeyemi and Obiyan 2009).

In some settings the discrimination could even be overwhelming. For example in Ganczak et al. (2007) college-based study on attitudes towards those living with HIV, 97% of the respondents prefer that all people entering United Arab Emirates (UAE) should be tested for HIV, while only 27% agree that children with HIV should be allowed to attend schools. Although HIV/AIDS stigma and discrimination hampers voluntary and confidential screening and counselling services (Brown, Trujillo and Macintyre 2001), however, the trend has continued, and no much progress can probably be made on mitigation unless it becomes unacceptable to discriminate against PLWHA (Fleischman 2005). Furthermore, WHO (2008), argues that because HIV is a life-long chronic disease which is highly stigmatised, those who are infected often have to deal with anger, fear and self-stigmatisation. Chilisa, Bennel and Hyde (2001) in outlining the effects associated with living with HIV/AIDS tabled the following: isolation, psychological trauma, emotional stress, demoralisation, de-motivation, anxiety, worry, sadness, fatigue, pain and agony, and so forth.

Studies have also acknowledged the anxiety felt by healthcare workers who come in contact with PLWHA (Hodgson 2006). One in ten doctors and nurses in Nigeria admit haven refused to care for HIV/AIDS patients (Ogunjuyigbe, Adeyemi and Obiyan 2009). Some dentists in Canada are also reluctant with treating HIV-positive patients (McCarthy, Koval and MacDonald 1999). An AIDS patient in South Africa (Sibusiso Mlangeni) said he received his first baptism of AIDS stigma from a nurse who said to him *"you`ve been messing around" "you have AIDS"* (Timberg 2005, 1). According to Kangasniemi (1996), many HIV-positive women are also stigmatised by non-specialised health care personnel.

In the 1980s, it was a requirement for many foreign students to take HIV tests before entering Finland, and such practice did not stop until after the members of Finnish AIDS Council demonstrated in front of Old Student House in Helsinki in 1987 (Clarke 2004). It was not until recently that the US travel ban on PLWHA was lifted (CDC 2009); and China followed soothe shortly before hosting the recent Olympic Games (Yuanfeng and Ying 2010). Nevertheless, there are still many countries in the world that either in full or in part have continued to refuse entry for PLWHA, and thereby continued to stigmatise and discriminate against individuals who in no wise pose threat to their national security.

Furthermore, PLWHA often face social exclusion which includes job and housing discrimination. An interviewee (Clarke 2004) was refused a job by an occupational health doctor simply because his medical records revealed that he is HIV-positive, and the doctor boldly told him that 'it is his responsibility to protect the company`s finance', and since he (the job applicant) has HIV, the doctor assumes that he may be taking sick leaves frequently or retire earlier than usual if employed. Similarly, in Cao et al. (2006) study of 'the reasons, sources, and types of HIV–related stigma prevalent in rural China', behaviours were primarily associated with fear of the disease rather than the route of it. Then in NordPol (2007), the respondents argued that sometimes people are afraid of them, and for that reason they often keep physical distance. All these show that HIV/AIDS discrimination is one of the greatest obstacles to preventing further infections, accessing care, support, and treatment services which enable PLWHA to live productively (Akinbami et al. 2010). Generally, HIV/AIDS discrimination has only been lightly challenged. Nevertheless, some have been working very hard to change the trend. For instance, since the 1980s the Finnish sexual equality organisation – SETA (Seksuaalinen tasavertaisuus) has persistently challenged the stigmatisation of HIV/AIDS in Finland (Clarke 2004).

### 2.2.6 Impacts of HIV/AIDS on education

Undoubtedly, education is the key to unlimited opportunities; however the opportunities may be dwarfed by HIV/AIDS (Gachuhi 1999). In fact, the disease has multiple negative impact on education, especially on the area of human resource-based development (Gachuhi 1999, Kelly 2000), however, the extent of the effects of HIV/AIDS on education remains unknown (Akunga et al. 2000). Pertaining students, Chilisa, Bennell, and Hyde (2001, 3) state that *"... knowledge and understanding about how the epidemic is affecting students remains very imperfect"*. But the education-related impacts of HIV/AIDS can be analysed in terms of demand, supply, and quality of education (Kelly, 2000). There is no doubt that teaching students who are sick, depressed, demotivated or demoralised affect instructional outcomes (Ibid). HIV/AIDS actually causes double- jeopardy situation which on one hand reduces the quality of education and on the other reduces the number of people who are able to attend schools (WHO 2002). HIV/AIDS also increases absenteeism from classes (Kelly 2001, Chilisa, Bennell and Hyde 2001), which in return effects academic performance.

#### 2.2.6.1 Impacts on primary and secondary education

In high prevalence settings like Sub-Saharan Africa, it seems that the impacts of HIV/AIDS on education are enormous, especially the impacts on primary education. Many primary school pupils are often forced out of school because families affected by the disease usually have fewer resources to send their children to school (FAO 1995, Kelly 2000, Akunga et al. 2000). In the case where children contribute to making-up for family income loss, the disease increases child labour (Isaksen et al. 2002). Still in high prevalence setting, children are also often withdrawn from school (mostly girls) to care for their sick parents

(Akunga et al. 2000). It also increases orphans` responsibilities after their HIV/AIDS parents` death which does not allow them to continue their education (Isaksen et al. 2002). Furthermore, primary schools are also affected by the decrease in the availability of teachers, administrators, and fund for education (Kelly 2000). Then AIDS` death decreasing the population size of a given community reduces the availability of school-age children (Kelly 2000, Akunga et al. 2000). Unfortunately, it seems that many of the effects of the disease on primary schools are also experienced at the secondary school level in such settings.

#### 2.2.6.2 Impacts on tertiary education

HIV/AIDS also affects community members of institutes of higher learning (mostly the female staff and students), and also their studies especially in the high prevalence settings. However, studies on the impacts of HIV/AIDS on tertiary education are scarce, and the available few seem to be too general. Furthermore, most of such studies investigated tertiary schools in Africa and few other developing countries. One of the few, Chilisa, Bennell, and Hyde (2001) study on 'the impact of HIV/AIDS on University of Botswana' discovered that HIV/AIDS attrition reduces university enrolment rates, and the disease`s related stress influences withdrawal from school. Particularly, in the academic year 1999/2000, the University of Botswana asked 132 students to withdraw from school due to poor academic performance, medical, and other private reasons (Ibid). To check such trend, Chilisa, Bennell and Hyde (2001) recommend that schools should provide HIV/AIDS friendly environment, and modules should be amended in ways that those students who cannot attend classes always will still benefit. In Finland and Nigeria there are no epidemiological studies on the extent tertiary students are affected by the disease, or to put it more accurately – there are none in English.

#### 2.2.6.3 Impacts on work and future goals

HIV/AIDS has strong impacts on the ability of an individual to plan and implement his/her future (Clarke 2004). But unlike in the 1980s and 1990s, PLWHA now live longer, healthier, productively, and much more in control of their future. Then while work is an important part of life, for PLWHA it particularly provide them additional access to health care, distracts them from thinking about the disease, allows them to contribute to the society, and serves in measuring health status (McReynolds 2001). Furthermore, unlike before the availability of HIV/AIDS treatments have also improved the chances of the PLWHA to become financial independence. HIV treatments have also helped in improving their work performance, work quality, quality of life, and most of all decreased their absenteeism from work (Beard, Feeley and Rosen 2009).

### 2.2.7 Costs of HIV/AIDS on Finnish and Nigerian societies

Caring for PLWHA undoubtedly improve their quality of life (Skevington, Norweg and Standage 2010). However, beside the costs on the individuals and

their families, caring for them is a heavy burden on a nation`s economy. In the Finnish welfare state, HIV/AIDS care could mean an additional burden on the already over-stretched welfare system (Sihvo 1991). For example, according to the Kluuvi Service Centre`s annual report on their HIV-positive customers, "*Not a single customer is in working life … 24% of the customers are on pension, 20% are on unemployment benefit, and 56% live on income support alone. Approx. 30% of customers are living on supported accommodation or a rented council flat and approx. 30% live on a financial obligation from the City in a lodging-house…"* (Aaltonen, Arsalo and Sinkkonen 2002, 199). While in Nigeria where welfare system barely exists, only about a third of those in need of ARV (antiretroviral medications) receive them despite the fact that her national HIV/AIDS burden is second only to South Africa (WHO 2007). But despite all these financial implications either on the part of the affected individuals, their families, and their nation-states, it seems wise that all hands must remain on desk in order to continually mitigate HIV/AIDS impacts which also checks the disease`s spread.

### 2.2.8 Vaccination, treatments, and cure for HIV/AIDS

Statistics show that adherence to HIV treatments slow down the disease`s progression. According to WHO (2010b) the progression of HIV in the body can be slowed to near halt with HIV treatments. Experts often argue that as a result of adhering to treatments, many PLWHA are alive today and are coping with the disease (Clarke 2004). Furthermore, Echeverria, Jonnalagadda, Hopkins and Rosenbloom (1999) attribute PI (protease inhibitor) treatments with weight gain, deceased viral load, increased CD4 counts, fewer opportunistic diseases, and better quality of life. However, because of ARV side-effects, caution should be applied while prescribing them (Zimmet 2005). But on the other hand, even in the midst of evidences that HIV medications improve health, some HIV-positive individuals still avoid using them for the fear that others might notice and discriminate them (NordPol 2007). Then, in addition to HIV treatments, PLWHA also need counselling, psychosocial support, access to good nutrition, safe water, and basic hygiene in order to improve their quality of life (WHO 2010b).

There is currently no sure vaccine or recognised cure for HIV/AIDS (Ristola and Sutinen 2002). Nevertheless, many of the PLWHA anticipate that a cure would be found in their lifetime. In expressing his hope for a cure, one of the participants in Anderson and Spencer (2002, 1345) states: *"I'm just happy to be here now and hope to be here when they find something."* Although efforts are being made on finding a vaccine for HIV, however, the success has been slow. The first land mark was made by a HIV vaccination trial conducted by the US army in Thailand which indicated up to 31.2% success (BBC September 2009). Then a newly FDA approved drug for HIV prevention (Truvada) is believed to have 44% to 73% capacity to prevent HIV (BBC May 2012).

Furthermore, while a recently concluded trial of Simian Immunodeficiency Virus (SIV) vaccine on monkeys proof very effective (Hansen et al. 2013), a Tampere based Finnish biotechnology company (FIT Biotech) in collaboration

with two leading European Universities plus one or two large American pharmaceutical companies is developing a unique HIV vaccine - Gene Transport Unit (or GTU). Although previous tests have shown that the vaccine may have the ability to stop the progression of the disease, or at best to eliminate the HIV virus completely. But to further measure its efficacy, there is yet another plan of conducting a large clinical trial soon; and it may take up to five years before the drug will be in the market (Yle December 2013).

### 2.2.9 Mitigating the impacts of HIV/AIDS

It seems essential that individuals who test positive to HIV/AIDS should be given as much support and empowerment as possible because the two somehow contribute to re-assembling their shattered lives. While support may be limited to lending a helping hand, empowerment goes beyond that and assists individuals in need to help themselves. A good way of differentiating the two is by comparing one (support interventions) to giving an individual fish to eat; which will make him/her to continue to ask for more, while as the other (empowerment) is like teaching the individual how to fish. For PLWHA, the two are essential for mitigating the impacts of the disease, but they need to be applied appropriately (Swidler and Watkins 2009)

With the look of things, it may take decades if not centuries for HIV/AIDS in human to become completely wiped out, because apart from the present high prevalence, many still do not know their status, and those who test negative today may not likely test negative tomorrow. Therefore it is essential for many to plan ahead so that the disease`s related diagnostic shocks will be minimised. For it is really necessary to prepare one`s mind for such unforeseen because there is the possibility for anyone to unexpectedly test HIV-positive tomorrow. So in view of this high prevalence, just like it is necessary to prevent the disease, it is also necessary to develop mechanisms for caring for individuals already affected; that is, the care which is both institutional and home-based (Otaala 2000).

Many of the PLWHA have continued to fight the impacts of the disease with optimism. For instance, in Anderson and Spencer (2002, 1346), one participant expressed his optimism this way: *"I'm a fighter and I'm never going to give up until they come up with a cure for this"*. In Fryback and Reinert (1999) study of HIV/AIDS and cancer patients, spirituality was observed to be influential in the patients` capacity to cope with the disease. But unfortunately even within the spiritual realm, some still see the disease as God`s punishment (Anderson and Spencer 2002). Of course, this is not surprising because HIV/AIDS has been a disease characterised with exceptional stigma and discrimination which must be well tackled in order to safeguard or minimise the chances of the PLWHA suffering identity crises, isolation, loneliness, low self-esteem, or lack of interest in fighting back against the disease itself (Valdiserri 2002).

#### 2.2.9.1 Empowerment: Sex education

Education stands out as the best empowerment for every individual. As such, in order to reverse HIV/AIDS epidemic, everyone especially youngsters need to be equipped with the knowledge and skills for protecting themselves against the disease (WHO 2002) because the chances of getting infected with HIV/AIDS and other STIs can be greatly reduced by avoiding high-risk drugs and unsafe sexual behaviours (Anderson and Spencer 2002). Gerouki (2010, 10) advocating for such intervention during school-age states, *"the school age is regarded as a very appropriate time for children to receive the first stimuli that will contribute to their proper psychosexual development"*. So it is necessary to communicate body changes and their social significance to youngsters (WHO 1984), because sexual knowledge improves sexual health (Herdt and Howe 2007).

But giving sex education has always been a controversial issue chiefly because of differing views of sexuality as a part of human identity and agency (Gerouki 2010). In Nigerian for instance, cultural factors makes the talk on sex a 'taboo', which has continued to give rooms for the increasing number of teenage pregnancy and STDs infections. The societal norms in Nigeria have also continued to affect the psychology of her young adults. For instance, I remember one afternoon during my junior secondary school days; after a given day`s studies was over, while walking behind a group of three female senior secondary school (upper secondary) students on my way home, without noticing that I was right behind them, they began to furiously expressing their anger over a just concluded biology class study on women`s reproductive system. One of them exclaimed *"we don`t need such lessons in a classroom setting!"*, another augmenting the comment said *"even if we need such lesson, the teacher should have selected the girls aside or better still send the boys out before teaching about a woman`s private part"*. They in that manner continued to express their dissatisfaction, and only pulsed after they noticed that I was right behind them. The view is of course because in Nigerian, societal influences to a large extent hinder sex education even at school. It is surprising to also know that even Greece amid her ancient civilizations is also struggling with giving sex education at school (Gerouki 2010).

In Nigeria and other developing countries especially in Africa where adequate sex education is wanting, teenage pregnancy is common (Ojengbede et al. 1987, Ogunniyi et al. 1991, Adekanle et al. 2008). But in Finland where sex education at school is relatively adequate, the abortion rate among teenage girls between ages 15 to 19 is under 15 in every 1000 teenage girls (Gerouki 2010). Gerouki (2010) further argues that because school is a place wherein young people project feelings of intimacy and sexuality manifested, the importance of communicating body changes and the social significance of it at school cannot be overemphasised, because if the youngsters are not duly given the ideal sex education, their peers and friends will give them the wrong ones, and the outcomes have always been anything but good. A Nigerian lady once narrated the

torments she passed through before knowing what menstrual circle is[17]. A somewhat similar incident is also said to have happened in Greece (Gerouki 2010, 22)[18]. So, it is worth noting that education is not designed to forbid sex or knowledge about it, but to support young people in making informed decision and thereby reducing the health risks of making misguided decisions (Suvivuo et al. 2009). So, surrounding sex and the education therein with secrecy does not reduce or quench young people`s desire for its exploration, but instead fuels it (Gerouki 2010).

Then pinpointing HIV/AIDS programmes within school sex education; they are mostly preventive oriented. It is therefore necessary to also include interventions which target individual students who are either directly or indirectly affected by the disease. Particularly, PLWHA may be useful tools for giving sex education aimed at making lasting impacts; because if a person living with HIV gives sex education to students, fear and prejudice may decreased, and the spirit of constant protective behaviour might be reinforced (Paxton 2002). Then though abstinence or the use of condoms remains the most effective means of preventing HIV and other STIs, recent studies suggest that male circumcision among other measures can reduce the risk of acquiring HIV though sex (WHO 2010b). Furthermore, in the western world promotion of condoms may go down well, but in Nigeria like other societies in Africa the promotion of condoms is a controversial subject, because such act is mostly assumed as a way of promoting promiscuous sex.

#### 2.2.9.2 Self-support

Anxiety, depression, and stress are common psychological problems among PLWHA, and managing such conditions are essential for coping with HIV/AIDS (Brown and Vanable 2008, Virk 2011). Farber, Schwartz, Schaper, Moonen, and McDaniel (2000) acknowledged that lower psychological trauma, better quality of life, self-esteem, and so forth enhances coping with HIV/AIDS. In addition, positive mindedness is equally important for coping with the disease. In Anderson and Spencer (2002, 1347), one participant expressed his positive mindedness thus: *"It's a sickness, but in my mind I don't think that I got it. Because if you think about having HIV, it comes down more on you. It's more*

[17] This lady grew up in a village setting where it is as usual a taboo to talk about sex either at home or at school. According to her story, at age eleven while she was circling to her parents' errand, suddenly she noticed that some body fluid had wetted her underwear. She ran into a nearby bush to find out what happened to her, surprisingly she noticed that she was bleeding. She was greatly frightened because she thought she has been infected with a deadly disease which has caused the bleeding. But unfortunately, the strong taboo surrounding talk on sex could not allow her to tell her parent [not even her mother]. So she thought she was going to die of a strange disease and soon. But about four days later the bleeding stopped, so she rejoiced that her deadly disease has been miraculously cured. Surprisingly, about a month later the same bleeding returned, and she thought of committing suicide before people will notice that she had contracted a deadly STI. According to the narrative, her greatest pain was not that she was going to die, but that though she was still a virgin; people will find out that she died of STI, and as such will believe that she contracted it sexually. However, while she was still battling within herself, the bleeding also stopped the second time few days later. She encountered the same the third month, fourth, fifth, sixth and so forth, without knowing what was wrong with her. So she later classified the deadly disease as the type which attacks her every month, and may continue until it will eventually kill her. So her ugly experience continued in silence and secrecy without her knowing what it was until after a year when an elderly friend told her about monthly circle.

[18] In Gerouki (2010) footnote number sixteen.

*like a mind game. To try and stay alive is that you don't even think about it. It's not in the mind".*

Furthermore, Holzemer, Henry, and Reilly (1998) study of 249 AIDS patients, discovered that, higher level of pain is associated with lower quality of life. But on the other hand, individuals living with AIDS attempt to control the progress of the disease by caring for themselves (Anderson and Spencer 2002), this is why healthy lifestyles which includes balanced nutrition is one of the most important aspects of HIV counselling; for it improves quality of life, sustains strength and body weight, replaces lost vitamins and minerals, improves the ability of the immune system to fight opportunistic diseases, keeps PLWHA active and productive, and so forth (FAO 2002). Then to adequately mitigate the impacts of HIV/AIDS, PLWHA need to take extra rest, stress less, keep positive attitude, take light exercise, seek counselling, accept help, quit smoking, avoid non-prescribed drugs, and refrain from alcohol which harms the body even more (Franceschi et al. 1990, Franceschi et al. 2006, Boffetta and Hashibe 2006, Allen et al. 2009, BBC April 2011, Yle September 2012), and as well influences unprotected sex. Accordingly, in NordPol (2007) survey, respondents said they started to eat healthier food after they tested positive. Many of the respondents also said they have reduced their alcohol consumption; nevertheless they still uphold the previous levels of their tobacco consumption. Particularly for the PLWHA, FAO (2002) pictures the circle of relationship between nutrition and upholding good health despite HIV-positive status as showed in figure one below.

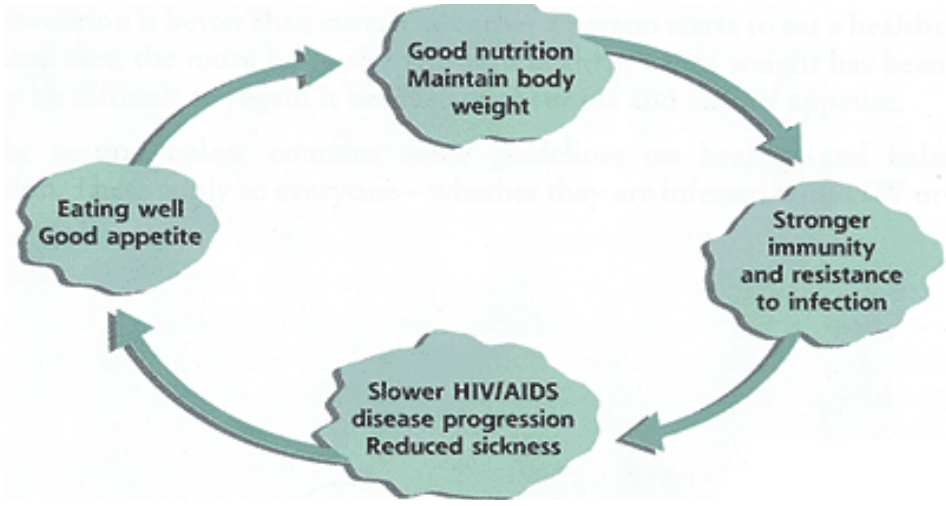


**Figure 1.** Circle on nutrition and staying healthy despite HIV/AIDS (FAO 2002)

#### 2.2.9.3 Social support

Community-based support is vital for improving quality of life (Yadav 2010), but for PLWHA the importance of such support is unquantifiable. As such, in

NordPol (2007) ‘quality of life survey’, nearly half of the respondents say they will start working if they receive extra support. A number of studies have also confirmed that there is a significant relation between social support and quality of life (Yadav 2010). However, thorough studies on factors which mediate the relationship between social support and health-related outcome or quality of life in PLWHA are lacking (Ibid). In Issiaka et al. (2001) study of the experiences of HIV-positive women in Burkina Faso, one out of every two women wishes to meet another infected person in their local NGOs to share viewpoints. As such, social inclusion is essential, and in fact somewhat contributes to the low rate of HIV/AIDS in Finland (Clarke 2004).

In many societies, family household is the first social safety net. For PLWHA, family`s support and comfort contribute to relieving the impacts of HIV/AIDS (Aga, Kylmä and Nikkonen 2009). But though families often demonstrate remarkably strong resilience in time of trouble, additional support is required by PLWHA (WHO 2002). However, the care and support from friends and family members should neither be too much or too little; because too much support may be overprotective, which removes the person`s dignity, sense of independence, and self-respect, while on the other hand, too little help may not provide the support needed to ensure that the person eats well and generate strength to resist infection (FAO 2002). Furthermore, Chilisa, Bennell and Hyde (2001) recommend that within and outside university campus, students living with HIV/AIDS should also support each other in order to promote positive living with STI/HIV/AIDS. As such, peer-support meetings are increasingly becoming popular (Harris and Larsen 2007). Such meetings among other importance promotes adherence to HIV/AIDS medications (Marino, Simoni and Silverstein 2007). On the other hand, the lack of confidentiality prevents HIV-positive individuals from seeking support, and to worsen the situation, even some of the PLWHA do not trust each other (Issiaka et al. 2001).

Furthermore, since testing positive to HIV is a big burden on its own, HIV/AIDS laws should in no wise add to the stress of PLWHA. For one of the most fatal things that can happen to PLWHA is for their remaining hope to be taken away, especially shortly after the HIV-positive diagnosis (Harris & Larsen 2007). So going by the existing HIV criminal laws, some legal scholars argue that, the laws are exceptional in the sense that they are enough to proof that the accused (a HIV-positive person) has engaged in forbidden act, which makes it appear as though safe sex is the sole responsibility of the PLWHA (Clarke 2004). Due to the exceptionality of HIV/AIDS laws, HIV/AIDS organisations have also joined the fight for the rights of PLWHA notwithstanding that their primary duty is to provide strong psychosocial support for PLWHA (Ibid). In summary, the concept map in Figure 2 below gives a compressed insight on many of what have been reviewed on HIV/AIDS in this section. Then because of all forms of mitigation against the impacts of HIV/AIDS, the most effective is ‘healthful living’, the next section is briefly on ‘education for healthful living’.

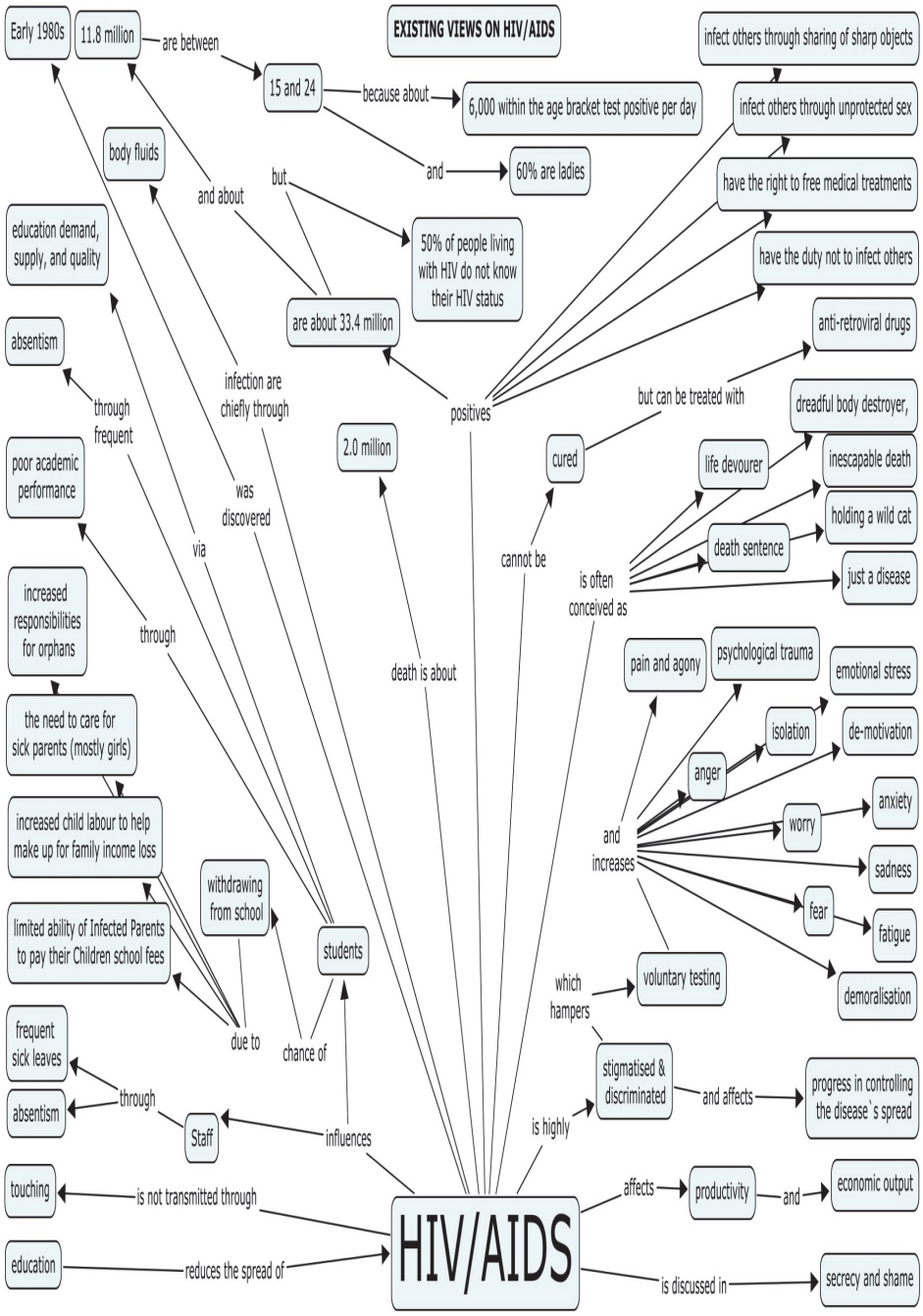


**Figure 2.** Concept Map on HIV/AIDS existing views.

## 2.3 Education for healthful living

It is no news that life has no duplicate, and as such should be well lived. For instance, equating human life to an automobile, if the owner does not handle it

with care, the vehicle sooner than its contemporaries will resist repairs at some point, fail inspection tests, and finally becomes forced out of the road. But on the other hand, with good maintenance an automobile will not only remain road worthy for a long time, but will save money and time which would have been wasted on avoidable patronage of the mechanics, because a stitch in time saves nine. This illustration gives a clue as to why while some individuals are healthy and happy, others are frequently ill, constantly visiting hospitals, and dying younger than their contemporaries. It is unfortunate that many are not well informed about their body physiology which would have guided them in giving a second thought to the toxins they constantly ingest or inject into their bodies to the detriment of their health. For while it is a privileged that many are born healthy, to remain relatively healthy for a long time requires among other duties self-control (Duckworth 2011) which helps in avoiding unhealthy but popular practices in our societies today, otherwise gravy consequences become inevitable. This is in agreement with Hardinge (2008) argument that during childhood we possess the body we are born with, in our adulthood we receive the body we gave ourselves, then in old age, we receive the body we actually deserve.

Right from 1948, the World Health Organisation (WHO) definition of health has remained unchanged; that is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO 1948). This definition although over half a century old, it still make a lot of sense in the 21st century because it is increasingly becoming clear that having no physical infirmity does not mean an individual is free from sickness; for one may be physically okay while socially or mentally the individual is very sick especially in this generation of increasing mental health problems (CDC 2013), which is also marred with social networks gradually stealing away face-to-face relationships. As such, this generation is becoming exposed to new sets of social health problems.

Furthermore, though technology especially in the 21st century has been helping humans in eradicating and managing diseases, however, the numbers of human diseases have been multiplying. Humans suffer numerous acute (diseases which have sudden onset and lasts for a short period) and chronic diseases (diseases which develop slowly but last long) (Dupree 2012). But while the acute ones are decreasing at this period of human history due to the eradication of pathogens which cause them through sanitation, modern medicine and technology, the humans` ever growing negative lifestyles are dragging down the successes. For instance the figure three below shows that heart disease, lungs infections, diabetes, cancers, strokes, and other chronic diseases are not just rampant but have over the years remained the leading causes of death. Instead of halting them, the very lifestyles which are responsible for the diseases are increasing and migrating even from the developed nations to the developing ones despite the fact that many individuals in such setting may hardly afford the cost of treating or managing chronic diseases (UN 1987).

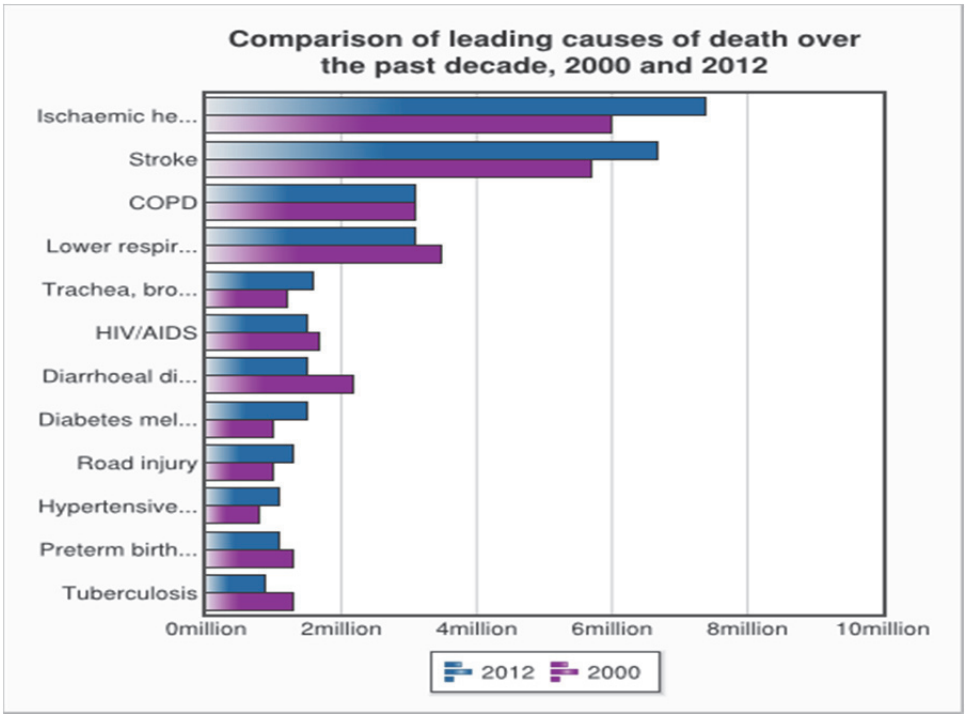


**Figure 3.** Comparison of leading causes of death in the past decade (2000 & 2012)[19]

Looking back at the 20th century, it was probably marred with the belief that modern medicine has almost all the answers to every disease. Even today, many still believe that they can live the way they want and if as a consequence of that they get ill, their doctors have readymade remedies for whatever illness that befall them. During the early 1990s when I use to work for Home Health Education Service (HHES), a man who refused to buy a set of health books I presented to him said, *"I don`t need the books because if I get sick I will see my doctor"*. This of course is not an isolated response or way of thinking; nevertheless, the tie is changing in the 21st century. Individuals have started to realise that good health is not just about medical treatments; rather it has more to do with inculcating positive lifestyle into daily living. Logically looking at it, that some medicines are not sold over the counter is not just to make individuals pass through doctors before purchasing them (although the world is becoming more capitalistic with doctors and other health practitioners giving less services for exorbitant charges – Yle June 2012d); it is much more reasonable that some medications are restricted to doctors` prescriptions because the side-effects of some medications in the long run are worse than the illnesses they are designed to treat.

[19] http://www.who.int/mediacentre/factsheets/fs310/en/

Beside prescription drugs, other common medications and some processed goods freely sold in grocery stores have their side-effects too, which proofs that for something to be legal does not mean that it is safe. A University of Edinburgh study of 663 patients between 1992 and 2008 reveals that the misuse of common analgesics like paracetamol can be very deadly because they may cause liver, brain, kidney, and breathing problems, or even death[20] (Simpson 2011). Cosmetic products as well, though their use are increasingly becoming popular; however a handful of them pose undesirable health threats too. For instance, some of the cosmetic products used for make-ups poison the body by increasing the amount of harmful chemicals absorbed into the bloodstream which is why a University of Turku Professor of physiology (Jorma Toppari) advises that cosmetics should either be moderately used or totally avoided (Yle July 2011b). However, in the midst of increasing health challenges, many have found the secret of regaining their health, and are taking advantage of it; that is positive CHANGES in lifestyles. For it seems very unreasonable to return to the very lifestyles which made one sick after a medical treatment, for if such trend is left unchecked, at a time it may render the subsequent use of a given medication ineffective, and the user becomes much more vulnerable and miserable.

Although it is believed that being educated improves health (UN1987), but the education in question here is not just receiving former education or acquiring degrees, but instead living out acquired health knowledge. So if there is a particular knowledge that is most wanted in the world today, it is the knowledge on human physiology and healthful living, but unfortunately many believe that such knowledge should specifically be reserved for doctors and other health practitioners. If many had acquired this knowledge, maybe there would have been less diseases and illnesses in the world, because knowledge being power would have probably compelled such individuals to live differently from the way they do now. But luckily, since 'free' is our friend, the 21st century has been characterised with the availability of internet`s versed health information most of which though amateur contain useful health facts of which exploring at no cost have been contributing to some individuals` healthful living and prevention of diseases.

It is also becoming clearer that medications are not the only remedy for treating illnesses. Going by the views of UN, the principal reductions in mortality rates in the industrial world came before the advent of modern medicines chiefly as a result of improved nutrition, housing, and hygiene (UN 1987). So it seems that there are many diseases which cannot be controlled or managed just through therapeutic interventions, because some illnesses are due to for instance nutritional deficiencies (Ibid), which is why in the 21st century, the treatment trend is changing from the modern medicine. Even some medical studies are now no longer wholly pharmacologically oriented, but are extending even to

[20] The study found that 161 individuals with an average age of 40 who had taken a staggered overdose (more than 500mg tablet a day) usually to relieve stomach or back pain, headache and toothache; two out of five died from liver failure – a higher rate than recorded for deliberate overdosing (British Journal of Clinical Pharmacology)

lifestyle or preventive medicine (Hensrud 2000) as they are being borrowed from the blue zones.

### 2.3.1 The blue zones

The term 'blue zones' seems to have been coined out by the 'National Geographic' to denote longevity hot-spots; where life expectances are longer than normal and habitants remain healthy and active even at old age. There are only a hand full of discovered blue zones; Loma Linda in the U. S., Okinawa in Japan, Sardinia in Italy, Nicoya Peninsula in Costa Rica, and Icaria in Greece. In these zones, acute and chronic diseases are far below the world`s average, and life spans are commonly beyond ten decades (Buettner 2008). So, what is the secret of the good health and longevity in these zones? Is it the people`s genes? Of course genes play certain roles in determining good health and longevity especially in the homogeneous blue zone settings like Okinawa, Sardinia, Nicoya Peninsula, and Icaria. But in Loma Linda, a heterogeneous setting made up of Whites, Latinos, Blacks, Asians, and so forth, the community`s logic is that genes determine just 25% of life span, and the other 75% is determined by how individuals choose to live. This argument has received many supports one of which is the Danish population-based twin study (Christensen, Holm, McGue, Corder and Vaupel 1999) which proves beyond doubt that genes play far less roles in determining health status especially when compared to lifestyles. In addition, Nedley (2011) argues that, a further insight into the first three blue zones reveals that while longevity is gradually declining among the Sardinians and Okanawins, it is actually increasing among the heterogeneous literate Adventist community. Figure four below shows the lifestyle traits which largely determine health and longevity, and how they are shared in Loma Linda, Okinawa and Sardinia.

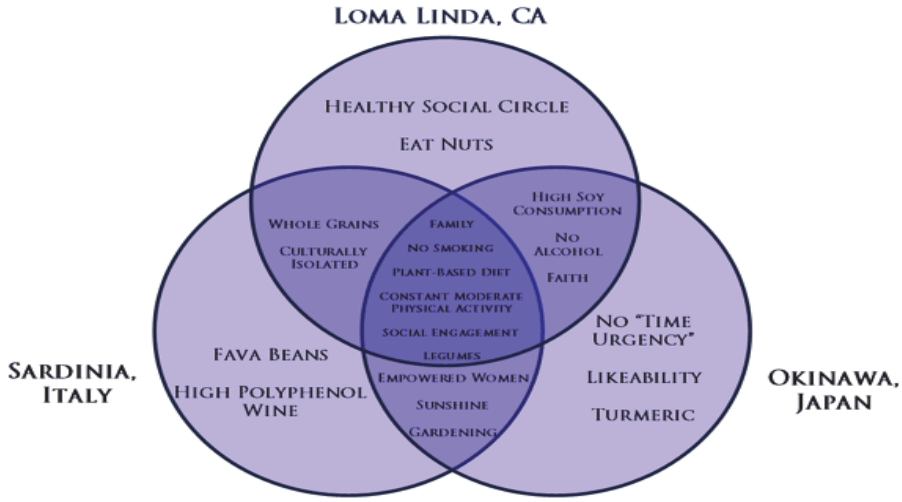


**Figure 4.** The secrets of longevity in three blue zones [21]

[21] Venn Diagram created by the Quest Network, retrieved from http://en.wikipedia.org/wiki/File:Vendiagram.gif

To further portray the above facts in a different way, in bluezone.com Dan Buettner and his team in what they called 'Power 9' outlined nine characteristic evidence-based denominators for health and longevity in the blue zones, they include: 1) Active lifestyle which is propelled by moving without thinking about it like growing gardens and other physical activities, 2) having a 'sense of purpose' in life; the Okinawans call it "Ikigai" and the Nicoyans call it "plan de vida;" both of which are translated to mean 'why I wake up in the morning', 3) routine or the culture of shedding away stress; the Okinawans take a few moments each day to remember their ancestors, the Adventists pray, the Ikarians take naps, and the Sardinians do happy hour, 4) a culture of calorie control which the Okinawans call '*hara hachi bu'*; that is – eating only until one is 80% full, 5) consumption of plant-base diets, 6) moderate or no consumption of alcoholic beverages, 7) belonging to a faith-based community, 8) putting family first – including keeping family members close to home[22], and 9) belonging to social circles which promote and support healthy lifestyle.

Furthermore, besides the Loma Linda community, studies show that Adventists in other parts of the world are generally known for their good health and longevity (Christensen, Holm, McGue, Corder & Vaupel 1999, Neiman 1992), and their guiding natural norms has been metamorphosed into the acronym – NEW START (Nutrition, Exercise, Water, Sun Light, Temperance, Air, Rest, Trust in Devine Power) (Comstock 2011, Weimar Institute 2013). Although the Adventist health norms seem significant, however, I did not explore them further in order to remain within the main context of this study.

[22] In contrast with sending the aged to the old people`s home.

# 3 METHODOLOGY

The predominant approaches to research studies have been qualitative and quantitative (but the combination of the two – 'mixed method' is increasingly being used – Creswell 2007). The differences between the two are well established (Siljo 1988, Fenstermacher 1986, Martin and Gaskell 2000, Morse and Richards 2002, Creswell 2003). So the brief comparison of the two is not aimed at labelling one better than the other, but to explain why one better suit my study. One fact that is worth noting about qualitative and quantitative approaches is that the two do not conflict with each other; rather they are both valid, and each has its advantages and disadvantages. For instance, while in quantitative studies a reasonable knowledge of the concept or phenomenon being studied is required in order for the researcher to be able to compare it with a predetermined standard of comparison (Creswell 2003), qualitative studies are based on the assumption that the phenomenon being investigated is unknown and requires exploration (Giarelli and Chambliss 1988), of which as far as the researcher knows his tools very well, he can study a phenomenon even if he is a novice to it, just like in this case.

Therefore, qualitative suits most this study because it enabled me to investigate the phenomenon (living with HIV) of which I knew little or nothing about prior to this study. Using qualitative approaches, I was able to explored the phenomenon as broad as possible because unlike in quantitative, there was no precategorised criteria or predetermined limit. For this study, qualitative was also chosen over quantitative because it improves arguments which have greater effects in practice (Fenstermacher 1986), and concerns itself with meanings rather than truths or building concrete knowledge. Qualitative approaches also explore and describe the variety of reality, and the conceptions people give to it as comprehensively as possible (Martin and Gaskell 2000).

Then within qualitative, there are many research approaches each of which is uniquely and relatively used. In an attempt to rationalise the approaches, Marshall and Rossman (2006) organised them into three groups namely: individual lived experience, society and culture, and language and communication. The approaches often used for studying individuals` lived experiences are phenomenology and phenomenography. Between the two, I had a long struggle with identifying which one will meaningfully answer my research questions. At first, I had no doubt in my mind that phenomenography will best answer my research questions until one of our lecturers who is an expert in phenomenology tried to convince me to use the later, and the struggle in choosing one out of the two benefited me a lot because it gave me the opportunity to re-evaluate the two very closely until I became well convinced that phenomenography which will attempt to describe relations between the HIV-positive students and the world around them will best answer my research questions.

## 3.1 Theoretical background of phenomenography

Phenomenography provided the philosophical foundation upon which the framework for the empirical data of this study was analysed. It is an approach within the interpretivist paradigm (Marton and Booth 1997) which is very descriptive (Marton 1986). Phenomenography has its origin at the beginning of the 1970s in Sweden, when two researchers (Ference Marton and Lennart Svensson) began a joint research project in the Department of Education at the University of Gothenburg (Dall`Alba and Hasselgren 1996). Their interest in exploring the relationship between *what* and *how* students learn, between the process and outcome of learning led them to place greater emphasis on *what* rather than *how much* the students learned, which ran contrary to the dominant paradigm (Ibid).

Phenomenography is often referred to as a method (Hasselgren 1996); Marton (1986, 31) further describe it as a *"research method for mapping the qualitatively different ways in which people experience, conceptualise, perceive and understand various aspects of, and phenomena in, the world around them"*. But Marton and Booth (1997, 111) state that, *"...it is not a method in itself, although there are methodological elements associated with it, nor is it a theory of experience, although there are theoretical elements to be derived from it"*. They further argue that experiences are essential for determining conceptions, and from the phenomenographic view; experiences are the only reality that exist (Siljo 1996, Uljens 1996). Phenomenography strives at describing all the relationships between individuals and their world based on conceptual thoughts and immediate experiences (Marton 1986).

In the phenomenographic approach, it is essential that the researcher reflects the variation within the population in terms of range of meanings, and not necessarily the frequency of ways of experiencing the phenomenon (Åkerlind 2005). In phenomenographic studies data is analysed together in search for qualitative differences in meanings within a group on the phenomenon being studies, and not an individual`s experience with or understandings of the phenomenon (Svensson 1997). It also does not focus on the phenomenon itself, but its relationship with the actors (Bowden 2005). So the object of phenomenographic research is not directly the surrounding world, but individuals' conceptions about it, which is known as the 'secondary viewpoint'. According to Marton (1981) objective knowledge about the environment does not exist; the only way to acquire information about the environment is through individuals` conceptions. Furthermore, phenomenography is interested in the range of understandings within a sample group as a group (Åkerlind 2005), therefore, it aims at describing the world, as a group conceives it in a manner that others could recognise and evaluate (Uljens 1996), and its research outcomes are often presented in unit of ideas called 'categories of description' (Åkerlind 2005). So phenomenography also depicts 'human experience' and emphasis on the journey instead of the 'absolute truth', and a phenomenographer analyses the experiences of others, and the data collection method includes interviews (Marton and Booth 1997). The approach requires that every interpretive step is made

clear to readers through giving clear pictures of the various stages the researcher followed (Åkerlind 2005, Stenfors-Hayes, Hult, and Dahlgren 2013).

## 3.2 The differences between phenomenography and phenomenology

There is no doubt that phenomenography (which is not yet recognised as an English word by Microsoft words) is an off shoot of phenomenology, but though they share some features such as 'human experience' as their object of research (Barnard, McCosker and Gerber 1999), nevertheless they naturally differ from each other (Marton 1986). To better capture the differences between the two, it is necessary to understand them from their Greek origins. The two originated from Greek compound words which shares one root word – 'phainomenon' (phenomenon) meaning: appearance or experience. While the Greek suffix of one is graphein (graphy) meaning: description, the suffix of the other is logia (logy) meaning: study. So going by the above etymology, while phenomenology means 'the study of appearance' [or experience], phenomenography means 'the description of appearance' [or experience]. It is for this reason that phenomengraphy pays attention primarily to the description of experiences rather than the study of a phenomenon. So while phenomenography is an empirical science, phenomenology is an epistemological project (Uljens 1992). Again while interpretive phenomenology focuses on the essence of the phenomenon, the focus of phenomenography is on the essence of the experiences and its variations within a group (Marton 1986, Hitchcock 2006). Furthermore, while phenomenology aims at capturing the richness of experience as it is described by an individual, phenomenography pays less attention to individual experience, but emphasis more on collective meanings (Barnard and Gerber 1999). So rather than studying the phenomenon (HIV/AIDS) itself as phenomenologist do, the goal of this study is to describe the conceptions of HIV-positive students on the disease primarily based on their understandings and experiences with it.

The above facts made it clear that while phenomenology seems more philosophical, phenomenography is much more practical. So this study being an empirical science on the collective meanings students living with HIV give to the disease, much attention was not paid to exploring the disease itself from epistemological stand points in search for the essence of the phenomenon or the richness of an individual`s experience, but rather a collective description of HIV-positive university students` experiences in Finland and Nigeria was done. Perhaps I would have use phenomenology as my research tool if my goal was only to study a particular aspect of HIV/AIDS or to explore a given area of its experience (e.g. the advantages of testing HIV-positive), but since my goal is to explore the entire picture of experiences with a disease I had only but limited knowledge of prior to starting this study with the aim of reaching particularly a group (students in limbo) who also probably have little knowledge about it, there was no better approach than phenomenography which enabled me to broadly explore and describe the whole picture on the experiences of HIV-positive university students.

## 3.3 Useage of phenomenography in this study

In accordance with Marton (1986) and other phenomenographers as explained above, the qualitatively different ways the HIV-positive university students conceive the disease are mapped and described in ways that all the conceptual thought (understandings) and immediate experiences expressed by the students on their relationships with the disease are reflected, and the variation within the participants in range of meanings are arranged in a manner that others could recognise and evaluate (Uljens 1996). Since my aim is to explore the meanings two geographically separated groups who share the same fate give to their experiences with HIV/AIDS, it was necessary to broadly compare how their responses relate and differ, so though phenomenography primarily guided this study, I simultaneously described and compared the results from the two groups (Finnish and Nigerian groups), in a unique approach I called 'phenomengraphic-comparison'.

Subsequently, concept maps are used as in sense of Åhlberg (1993, 2004 and 2013) and Wheeldon & Åhlberg (2011) to create overviews of concepts/conceptions, their classification and their main relationships at the end of every category of description to separately show the Finnish and Nigerian participants` conceptions within each category. To further illustrate the outcomes, tables of comparison were use in the appendixes one to seven to compare Finnish and Nigerian participants` conceptions thematically in relation with facts from the literature. Then 'propositions in text formats' from the concept maps was also used in appendix 8 to present the concept maps on the participants` conceptions through a different light.

## 3.4 Data collection and analysis

This section gives brief details on the participants, and what is ethically done to avoid the study from hurting them. Also in a step by step procedure, explanation is given on how the research data was collected and analysed with illustrations on the process followed in analysing the data.

### 3.4.1 Finding participants

Initially I planned to travel to many parts of Finland to interview the participants of this study, but before long I realised that finding participants was going to be tougher than anticipated due to the sensitivity of the study. So after several attempts, I managed to find three participants, and unfortunately the three are from Uusimaa Region. I was lucky to be linked to the three through 'Body Positive' (a Finnish HIV/AIDS organisation). Further efforts to find more Finnish participants were fruitless. The only person from another region who would have participated in the study unfortunately opted out as entitled to. Beside the limited number of PLWHA in Finland – 2600 (UNAIDS/WHO 2008), and the fact that the study participants are limited to HIV-positive university students, perhaps the difficulty in finding Finnish participants was also because the PLWHA in Finland often shy away from giving interview (Clarke 2004).

The Nigerian participants were also contacted through a HIV/AIDS organisation (Hope Worldwide) in Lagos. The organisation requested for a 'letter of introduction and commendation' from my supervisor, and after submitting it, her management helped in reaching out to the PLWH who fall within the criteria required for this study, and also provided a place where all but one were interviewed. But due to some challenges, I was only able to interview four participants before my stay in Nigeria was over.

### 3.4.2 The research subjects

A total of seven individuals participated in this study all of which are ladies; three and four from Finland and Nigeria respectively. They tested positive to HIV through maternities, diagnostic laboratories, needle exchange centre, and sexual health clinic. While the Finnish participants are not public about their status, the Nigerians (except one) are public about theirs. All of them are on medications. Two of the Finns are still studying, while one has graduated, and two among the Nigerians had graduated (but one of the two re-enrolled for another course of study), while the other two are still studying. Among the Nigerian participants, one attends 'Collage of Education', (which is a tertiary institution primarily dedicated to training Nigerian teachers). One in each country is in full time job. Two Finns and two Nigerians tested positive before gaining admission into the university, while others tested positive while already in school; even one of the Nigerian participant tested HIV-positive shortly before her graduation.

Furthermore, one of the Finns is in a relationship with a HIV-negative man, while the other two are still searching, and each of the two has a HIV-negative child. All their Nigerian counterparts are in relationship with HIV-negative men, three of them are married, and one is yet to, two of them also have two HIV-negative children, while a third has one. One of the Finnish participants is a committed Christian, while the other two are not too keen about religion. Then while three of the Nigerians are committed Christian, the fourth is a committed Muslim. As at the time the Finns were interviewed, the participants were about 26, 36, and 45 years of age, and had lived with the disease for about 7,12, and 20 years respectively. Their Nigerian counterparts were about 23, 28, 31, and 41 years of age, and had lived with the disease for about 9, 8, 8, and 12 years respectively. If I have had my way, I would have interviewed more students and limited the participants to only university students who are presently in school because the study is tagged 'students' and not 'graduates', but difficulties in finding participants made it 'a mission impossible'.

### 3.4.3 Ethical issues in brief

Ethics is a broad field. As a concept guiding medical and social studies it has a long history which dates back to the 'Declaration of Helsinki' in 1964 (Snežana 2001). Particularly from social research ethics dimension; in as much as it is essential for a researcher to provide retrievable data, for ethical reasons it is also his/ her obligation to do his/ her research subjects no physical, emotional, or

psychological harm[23]. As such, protecting them should be his/ her priority upheld through not revealing confidential or identifiable information about them and also that of related third parties. So, researchers ought not to directly cite their study participants, but instead discuss the data gathered from them in confidentiality. Nevertheless, to uphold fidelity and scientific integrity, it is also important that while employing certain strategies to protect participants, facts are not twisted in ways that may lead readers to draw false conclusions. So, to arrive at the required ethical standards, some numbers of steps were followed while doing this study.

First, the interview of those who participated in this study was completely on voluntary basis, and to minimise their fears of being harmed, at the beginning each interview, the participants were assured that their identities will be kept secret, and the plans for achieving that was revealed to them. Although the study is a sensitivity one, ethical clearance was not obtained before its data collection commenced because the study needed only but a small number of participants, instead a 'letter of introduction and commendation' from my supervisor was used. So, from the beginning to the end of the study, measures were taken to ensure that the study will not hurt those who participated. Particularly in the presentation of the results, some facts were withheld in order to avoid giving rooms for the participants to be identified; for example, the cities and countries outside Finland where some Finnish participants had lived and where they tested HIV-positive were withheld. The name of their schools and their present residential cities were also withheld. Then as a study involving participants from two countries, their responses were judiciously compared.

Furthermore, to give readers good insight on who said what, and at the same time ensure that the participants` identities are well protected, instead of 'pseudonyms' (fictitious names) I used numbers and figures to represent each of the participants in form of 'reference codes'. The codes are made up of letters I agreed with some of the participants. The letters representing their sex and nationalities, and the figures were derived from the year each of them tested HIV-positive, and their presumed year of birth. Table 2 below contains a brief description of how I arrived at the reference codes used for each participant.

[23] Most times ethical clearance is required before the commencement of field studies.

**Table 2.** Brief description of the reference codes used for each participant

| Num. | Chosen Letters | Figures from yr. of testing positive | Figures from yr. of birth | Sex: Female | Nationality: Finland/Nigeria |
|---|---|---|---|---|---|
| **1** | sh | 04 | 85 | f | f |
| **2** | sn | 99 | 75 | f | f |
| **3** | ms | 93 | 67 | f | f |
| **4** | tp | 03 | 89 | f | n |
| **5** | ht | 04 | 84 | f | n |
| **6** | as | 04 | 81 | f | n |
| **7** | aw | 00 | 71 | f | n |

So, the reference codes for the participants are: sh0485ff, sn9975ff, ms9367ff, tp0389fn, ht0484fn, as0481fn, and aw0071fn, and for accountability, each time a quote is used in the outcomes, the reader will find the code right at the end of the quotation in brackets to determine who said what. This also helps in judging if the distribution of quotes is balanced, but it is not designed to categorise or measure the experiences of each participant with the phenomenon because a given participant might have forgotten to give certain details, or preferred not to share given information with the researcher due to personal reasons, or perhaps did not reflection seriously on the phenomenon during the interview.

### 3.4.4 Data collection

Through a semi-structured interview questions, the data for this study was collected. I used four main questions and several sub-questions. Most of the questions were not predefined in order to give rooms for unexpected answers (Ely et al. 1997), and some of the sub-questions were based on each participant`s earlier response. Out of the three Finns that participated in this study, two were interviewed face-to-face, while one who did not want me to see her face choose to write instead. Flick (2006) counsels that email interview can be used. Believing that if I send all the questions at the same time, they will be boring and discouraging, and this participant may not respond to them duly, I sent the interview questions to her bit by bit until I gathered what I presumed to be enough response. But because she chooses to write, her answers were generally short. The other two, I separately engaged in in-depth interviews which lasted for about two hours because the interview continued until there were no more new ideas.

The four Nigerians that participated were also interviewed face-to-face. The interview of three of them lasted for almost 2 hour each, while the fourth lasted for little below one hour[24]. The total interview time with the Finnish and Nigerian participant was almost 9 hours. The Finnish data was collected in 2011, while the Nigerian was collected in 2012. Although the participants are only seven in number, they served for this study because in phenomenographical investigations, data can be gathered from a small number of individuals, but in that case the outcomes will not be expected to be exhaustive (Marton and Booth 1997).

### 3.4.5 Processes of data analysis

In phenomenographic study, it is important that a researcher exclusively use his data because all the material therein forms a pool of meanings which the researcher needs, and it is his task to find them (Marton and Booth 1997). Using my chosen approach, the first step was to repeatedly listen to the recorded responses of the two and four interviewed Finnish and Nigerians participants respectively. Subsequently, I transcribed them. The transcriptions were verbatim without skipping grammatical errors, stammering and repetitions made by the participants. In addition, the data collected via email was also arranged like the transcribed ones. Followed was my familiarisation with the data in search for relevant points from the participants` responses using my research questions as a guide. To explore all possible perspectives, I did multiple readings (Prosser 1994), which helped me to test the agreements between my research questions, interview questions and the participants` responses. Then I continued the process of familiarisation, but this time with my research questions in mind, and that also continued until meanings began to emerge, and I was able to select the most relevant quotations from the data which apply best to my research questions.

Furthermore, I printed out the whole data, and starting with each of the Finnish participants I cut out selected relevant responses which in my opinion is in concord with my research questions, and based on the idea expressed I grouped them into themes. Again, based on their similarities and differences, the Finnish and Nigerian group themes were separately classed into categories and subcategories, and ideas compared. The units of ideas formed afterward known as ‘categories of descriptions’ (Åkerlind 2005) emerged, and seven of them shaped the theories of this study. Ideally, the categories may be hierarchal, vertical or horizontal, but often the hierarchal categorisation is used in phenomenography to search for the hierarchy in the participants` responses from the most efficient to the least which is known as ‘outcome space’ (Marton and Booth 1997). However, in this study, no outcome space was used because judgements were not made as to which opinions are better or efficient than others, but the responses of all the participants were placed on equal importance.

[24] The shorter interview here was because most of the participant`s responses are similar to those of the earlier three

The formed categories were examined repeatedly, and the differences and similarities further identified, adjusted, and readjusted until the rates of changes minimised, core meanings stabilised, and a clear image of the phenomenon emerged (Marton 1986). Haven examined the entire text, and all relevant quotes contextually vetted (Marton and Booth 1997, Åkerlind 2005), the structural relationship between the categories were weighed (Åkerlind 2005). Throughout the analytic process I maintained open mind as counselled by Åkerlind (2005, 323) that, "*Paramount is the importance of attempting, as far as possible, to maintain an open mind during the analysis, minimizing any predetermined views or too rapid foreclosure in views about the nature of the categories of description. The researcher needs to be willing to constantly adjust her/his thinking in the light of the reflection, discussion and new perspectives"*.

In order to avoid disjoining of the participants` ideas and uphold their original thoughts, I kept my interview questions attached to the responses throughout the process because the nature of every participant`s ways of expressing herself is highly contextual. Then while writing out the results in chapter four, I quoted the participants verbatim (Marton and Booth 1997) because it is their` own words that attention should be drawn to and not that of the researcher. So, their grammatical errors, spelling errors, and so forth were not omitted, because phenomenographic studies attempt to describe the entire conceptions of participants, and as such the researcher needs to be as neutral as possible throughout the analytic process. In the presentation of the outcomes in chapter four the quotations from the two groups in their themes were compared and re-examined. Figure five below shows the process followed the data analysis.

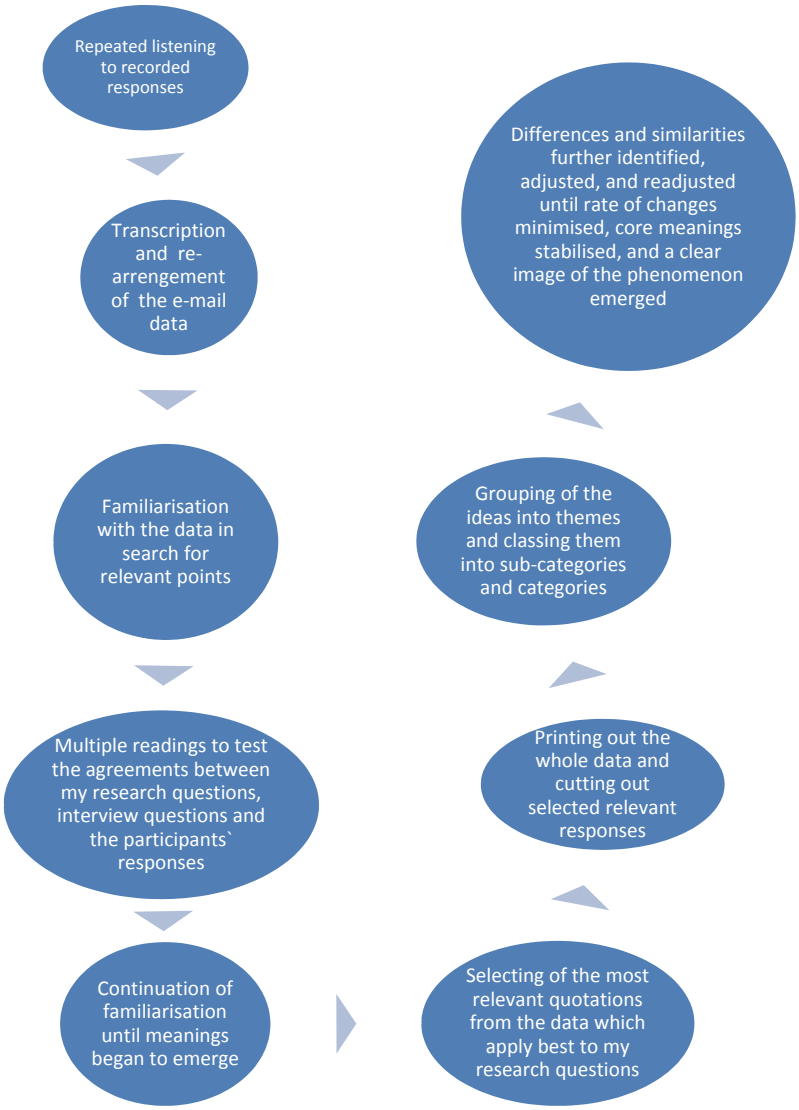


**Figure 5.** Processes of data analysis

# 4 DESCRIPTIVE COMPARISON AND EXAMINATION OF RESULTS

This chapter described, compared, and examined the results that emerged from the responses of the three Finnish and four Nigerian participants as explicit as possible using phenomenographic categorisation (categories, sub-categories, and themes). As explained earlier in chapter three, because the phenomenographic approach is primarily for identifying qualitatively different ways a phenomenon is conceived, this study being a cross-national one, the approach was uniquely used in what I called 'phenomenographic-comparison of outcomes', which gave me the opportunity to compare and describe both the similarities and qualitative differences in the participants` conceptions of HIV/AIDS. Furthermore, concept maps (propositions in map forms) were used to show the Finnish and Nigerian participants` conceptions separately at the end of each category, and text formats of the 14 concept maps that emerged were presented in appendix eight to further illustrate the outcomes. But prior to that, thematic tables of comparison (tables 7 to 32) were used in appendixes one to seven to give vivid pictures of the similarities and differences in the conceptions of the Finnish and Nigerian participants in relation to the theories and hypothesis from existing literatures.

In order to adequately illustrate the variation between participants` responses in this chapter, quotations were made under each theme in the sub-categories as often as they were necessary in order to keep the attention on the participants` own voices. However, the title given to the themes under which the participants` conceptions were described and compared did not necessarily emerge from the participants` own words, but were chosen because each describes a particular idea in the context best. Also the themes in each sub-category were arranged in the order that made it easy for the Finnish and Nigerian participants` responses to be compared based on similarities and differences, and also the themes were uniquely written to make them look different. The quotes were put in italic, and reference codes for each participant were attached to identify who said what in place of the participants` names to minimise the chances of tracing their identities. How the reference codes emerged is explained in table 2 in chapter three.

The participants` responses were analysed individually and in each group, and based on their conceptual thoughts and immediate experiences meanings of living with HIV as a university student were comprehensively and explicitly explored and compared. The exploration led to the emergence of 7 main categories of description, 26 sub-categories, and a total of 300 themes (155 and 145 from the Finnish and Nigerian participants respectively) as illustrated in table 3 below. All responses from the participants were treated equally, and none was designated right or wrong, so whereby more quotes were made from a given participant`s responses, it does not mean that others agree or disagree with her.

Furthermore, in the comparison of the similarities and differences between the Finnish and Nigerian participants (whom I sometimes referred to as 'Finnish group and Nigerian group'), responses are made explicit starting from where the two agreed to where they disagreed, and whereby in a theme there are differ-

ences in the responses of members of either group, the differences within the group are also made explicit, and where the titles of similar themes presented together differ, the themes for the Finnish participants and the responses therein are presented first. Theme names were written in bold letters but not numbered. Also in the sub-categories where positive and negative conceptions occurred together, the positive ones are presented first. Then a summary of the outcome of every sub-category are given at the end of each.

In the first category, I started by comparing and describing the participants` earlier understandings of the disease, how it framed their initial views of it, and what their views are now they are HIV-positive. Afterward a brief insight on their knowledge of the disease`s origin was explored, I sorted for their understandings on the negative and positive sides of the disease. Categories two to four described and compared the negative and positive impacts of HIV on health. Using the WHO definition of health as a guide, I analysed the impacts of the disease on emotional/ mental health, physical health, and social health in each category. Category five described and compared the negative and positive impacts of the disease on education. Category six described and compared the negative and positive impacts of the disease on productivity and future goals. Then category seven comparatively singled out the positive lifestyle changes in the participants which resulted from their HIV-positive status. As shown in figure six below, the 7 categories under which the outcomes of this study is described and compared are: 'Knowledge and understandings on HIV/AIDS, Impacts of HIV on emotional/ mental health, Impacts of HIV on physical health, Impacts of HIV on social health, Education-wise impacts of HIV, Impacts of HIV on productivity and future goals, and Transformations after testing HIV-positive'[25].

[25] HIV only was used here instead of the usual – HIV/AIDS because all the participants claim to be living with HIV and not AIDS, so in subsequent passages where I exclusively refer to the participants of this study, HIV is used instead of HIV/AIDS.

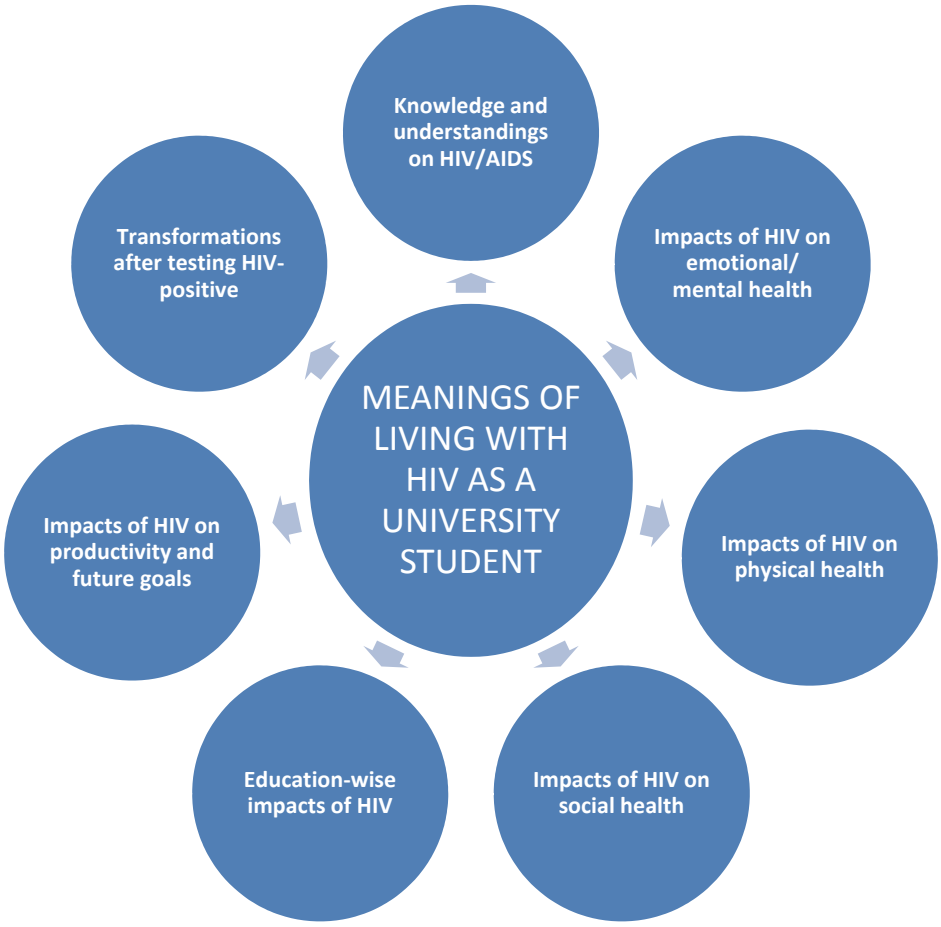


**Figure 6.** The seven main categories of description

**Table 3.** Categories, sub-categories, and themes emerging from results.

| Categories (7) | Sub-categories (26) | Total Themes (300) | Finnish Themes (155) | Nigerian Themes (145) |
|---|---|---|---|---|
| **Knowledge and understandings on HIV/AIDS** | Initial knowledge, Present understandings, The origins of HIV/IDS, Negative sides of HIV/AIDS, & Positive sides of HIV/AIDS | 51 | 29 | 22 |
| **Impacts of HIV on emotional/ mental health** | Getting tested, Testing positive, HIV acceptance, Emotional ttress, & Coping strategies | 56 | 29 | 27 |
| **Impacts of HIV on physical health** | Physical health conditions, & Medical treatments | 24 | 12 | 12 |
| **Impacts of HIV on social health** | Opportunities forgone, Disclosure of positive status, Experiences with stigma & discrimination, Impacts on relationships, & Impacts on faith & spirituality | 64 | 31 | 33 |
| **Education-wise impacts of HIV** | Knowledge and awareness, Experiences at school, Alteration of study plans, & Motivation for academic pursuits | 40 | 19 | 21 |
| **Impacts of HIV on productivity and future goals** | Work & productivity, Fears and worries, & Hopes | 34 | 20 | 14 |
| **Transformations after testing HIV-positive** | Transformations due to new self-perceptions & Reformed lifestyles | 31 | 15 | 16 |

## 4.1 Knowledge and understandings on HIV/AIDS

Knowledge and understanding are sometimes used together or interchangeably, and to some they appear to mean the same thing. But though they are closely related, they are not the same. While knowledge is often used to depict what is known based on information acquired, understanding is more about an individual`s views based on the interpretations given to the information received or acquired. There could be other ways of interpreting these twin-words, but in the context of this study, the above explanations are what they are used to illustrate.

Knowledge and understandings on HIV/AIDS vary widely between the Finnish and Nigerian participants, however, in some number of occasions they share the same views. This category is primarily based on the Finnish and Nigerian participants` conceptual thoughts. Here comparative descriptions of the participants` initial knowledge, present understandings, ideas on the origin of the disease, negative sides, and positive sides of the disease were explored, and the aims for the comparisons are manly to identify as wide as possible what the

participants believe constitute the problems with HIV/AIDS, and their other knowledge on the disease. As shown in figure 7 below, this category is compared and described under 5 sub-categories.

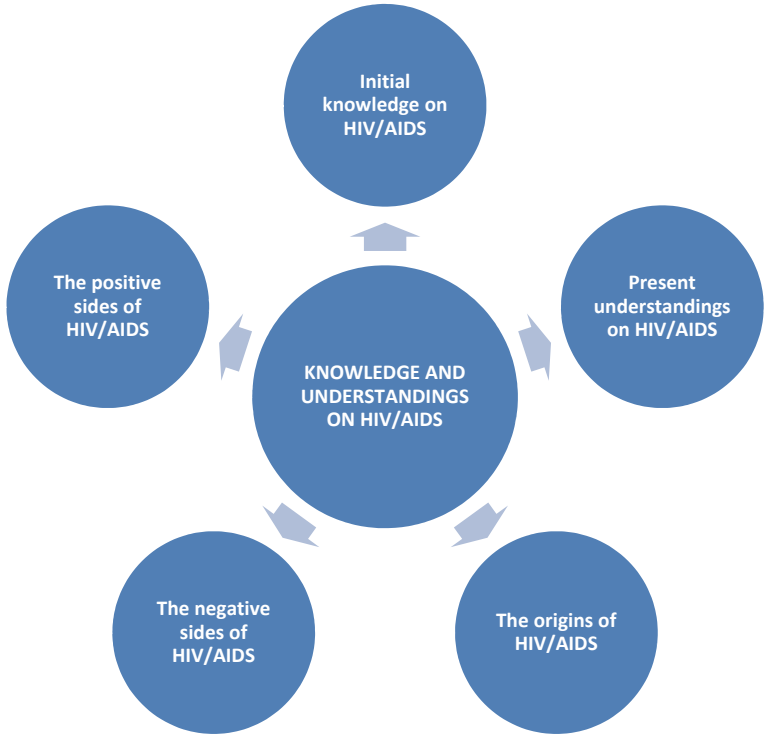


**Figure 7.** Knowledge and understandings on HIV/AIDS

### 4.1.1 Initial knowledge on HIV/AIDS

Knowledge on HIV/AIDS varies from person to person. It is often based on individuals´ exposures, circumstances, environments, experiences, and so forth. Fortunately people`s knowledge on the disease have been evolving positively, but only at a low pace. This sub-category examined and compared the participants` knowledge prior to their testing positive to HIV. The initial knowledge of the Finnish participant were 'something that happens in Africa, death sentence, gay disease, something dirty, something scary, and a reason to give-up all responsibilities', while the Nigerian participants` initial knowledge were, 'not made for me, deadly disease, and no idea'.

**Something that happens in Africa/ Not made for me:** HIV/AIDS is a scary disease which should be avoided as much as possible. However, an individual to image it as something very far away or something designed only for other gives nothing but false hope, as in the case of two of the participants. Like many other Finns, one Finnish participant prior to her testing positive to the disease

did not just think that the disease is far from her, but also saw it as something that happens in far places like Africa, and so has nothing to do with her, and that she expressed thus:

*So I was saying like many Finnish people it doesn`t affect their lives. I have to admit that I thought is something that happen maybe in Africa and have nothing to do with my life (sh0485ff).*

Similarly a Nigerian participant who initially thought that she will never contract the disease said:

*Before I know my status I think HIV was not made for me, I think I don't have any business with it (ht0484fn).*

So either in Finland, Nigeria, and other parts in the world, it is the failure of individuals to see themselves within the high-risk group, or commit to safe sex [and other healthful practices] that has continue to facilitate the spread of HIV (Durojaiye 2011).

**Death sentence/ Deadly disease:** Going by the dominant paradigm death is often the first thing that comes to mind any time HIV/AIDS is mentioned. Although this view is declining, but it still exists. One Finnish participant in expressing her initial plot on the disease said she thought it was a

*...death sentence (ms9367ff).*

Another Finnish participant who shared similar view said:

*In the beginning I really thought that am going to die soon, younger, or something (sh0485ff).*

Similarly, the participants in Anderson and Spencer (2002) see the disease as a life devourer, and since nobody wants to die except for those who are psychiatrically sick, the disease being seen as a death sentence is one of the reasons why HIV/AIDS is greatly feared. A Nigerian participant who also uses to see the disease in the same deadly light further expressed that she uses to think that HIV and AIDS are the same:

*When I was still young, I use to hear about HIV, I thought it was a deadly disease, I even thought HIV is AIDS, I never believe there is difference between AIDS and HIV (as0481fn).*

So beside the needless thoughts of the disease to be deadlier than it really is, there are many who still think that HIV and AIDS are the same, while as in reality the two differs as explained in the literature review.

**Gay disease:** The oldest view on HIV/AIDS in Finland which still exists to some extent is 'gay disease'. This is probably because in the Finnish context, the primary framework for understanding AIDS is 'gay plague' (Clarke 2004). Holding on to that view may have been influence by the fact that the first five people to be diagnosed with AIDS in Los Angeles were gay (MMWR 1981). No wonder a Finnish participant said:

*When I was about 17, the first case came public, he was that actor Rock Hudson. We just laughed about aids and thought it was for gays only (ms9367ff).*

From the response of this participant, we will see that she also thought that the disease will not reach her because she is not a lesbian, but she was dead wrong. However, in Nigeria where the gay community barely exist, none of the participants sees the disease in the context of gay plague.

**Something dirty:** Since the disease was originally and exclusively associated with gay, its discovery at a time when the gay community was not embraced in the Finnish society as it is today, might have made the disease to be seen as something dirty. But as the demography of the PLWHA in Finland in the 1990s extended to include drug users and immigrants, the view on the disease got even dirtier. No wonder a Finnish participant said:

*Well, I thought it was somehow like you know dirty, and the people with the disease are dirty, and I considered myself very dirty as well when I first got it (sn9975ff).*

In fact, the whole scenario went to the point that a vocal camp began to suggest strong managerial responses that include quarantine (Clarke 2004), or sending infected people to unused leper colonies (Clarke 2002). Another Finnish participant who was also influenced by the view once saw the disease as a social recluse that calls for infected individuals to voluntarily isolate themselves from the society.

*Social recluse (ms9367ff).*

Although the Nigerian participants did not use such expression to describe their initial view on the disease, such view exists in Nigeria which is why more than 50% of Nigerians say they cannot shake hand, hug or share the same toilet with PLWHA (Ogunjuyigbe, Adeyemi and Obiyan 2009). In the minds of many Nigerians, dying is not their greatest worry; rather it is that people will know that they died of AIDS, and the reproach it will bring to their families.

**Something scary:** Following the discovery of HIV/AIDS in the early 1980s, the first few publications painted gloomy and scary pictures of the disease. The image created then was of a disease that reduces an infected person to skeleton before it finally kills the individual. More also the disease being linked to Kaposi's sarcoma (a cancerous tumour of the connective tissue which grows under the skin, in the lining of the mouth, nose, and throat, or in other organs) made it to appear more dreadful. The initial views of two Finnish participants (one of whom heard about the disease before the age of ten) are expressed thus:

*I was under 10 years old and maybe really scary thing (sn9975ff).*

*Kaposi's sarkoma in the face (ms9367ff).*

The views are in agreement with Anderson and Spencer (2002) study on the cognitive representations of AIDS where a participant pictured the disease as

*"Pain from head to toe, no hair, 75 pounds, can't move, can't eat, lonely and scared. Family loving you and you can't love them back."* Though such views on the disease are changing, it is still seen as a scary thing in the Finnish and Nigerian context.

**An opportunity to give-up all responsibilities:** HIV/AIDS been envisioned by many as a dirty, fearful, and deadly disease of which Anderson and Spencer (2002) captured as 'people who are reduced to skin and bones, extremely weak, in pain, losing their minds, and lying in bed waiting for the end'. So a Finnish participant who was once an IV drug user had also thought that she was never going to get infected with the disease, however, in her mind she made the provision that if she gets infected with the disease it will be an opportunity for her to give-up all responsibilities and continue to enjoy her misery. The view she expressed thus:

> *I thought well if I someday get HIV, I just give-up my responsibility and everything and just keep doing [drugs], but it was something scary (sn9975ff).*

**No idea:** Surprisingly, a Nigerian participant who tested positive to HIV in the year 2000 said prior to her testing positive to the disease, she had no idea what HIV was. In her words she said:

> *I was so innocent; I didn't even know what it is, I didn't know what it is. (aw0071fn)*

Of course Nigerians are not the only ones in such ignorance, in countries like Bangladesh only about one in every five married women have heard of AIDS (UN Women 2011b), but in Nigeria where the disease has been rampant, so it sounds strange that an enlightened woman who lives a civilised city like Lagos had not heard about the disease before the year 2000. This shows how little some Nigerians know about the disease especially in the rural communities, but the trend is somehow changing.

### 4.1.2 Summary of initial knowledge on HIV/AIDS

In this sub-category, a total of nine themes (six and three from the Finnish and the Nigerian participants respectively) emerged on the participants` initial knowledge of HIV/AIDS. The themes show that the initial knowledge of the two groups agreed in identifying HIV/AIDS as a fearful and deadly disease that is far away. But while the Finnish participants once perceived it as gay, something scary, something dirty, and a reason to give-up all responsibilities, a Nigerian participant surprisingly said she knew nothing about the disease until she tested positive to it in the year 2000. Of course it sounds strange especially when compared with the Finnish participant who said she heard of the disease before she was 10 years old. That shows how much in dark many Nigerians had been until recently. So there is a great need for more HIV/AIDS enlightenment in Nigerian and other developing countries. In part the reason why ignorance persists in Nigerian is lack of [or limited] access to information due to poor electrical power supply, limited access to the internet, coupled with the people`s

low income per capital which makes it difficult for many Nigerians to afford educative services. While as in the Finnish welfare state, income is far better, electrical power supply is constant, internet services are readily available for most people, and education services are free.

It is understandable that the Finnish participants initially identified the disease solely with the gay community while the Nigerians did not because in Finland gay was the primary plot by which the disease was identified, while as in Nigeria where gay community barely exists, it has always been seen only in the light of sexual promiscuity probably because the two championing religions (Christianity and Islam) distastes homosexuality, and families and most communities forbid it too. So since the religious bodies and families are the only functional safety net in times of crisis, people with such sexuality often operate behind the counter. Then though the struggle for the Finnish state church to completely accept gays ranges on, she is much more lenient to the community than her Nigerian counterparts.

Another differing view is where a Finnish participant said she use to see the disease as a reason to give-up all responsibilities. There are people who probably have no goals or sense of responsibility in life, individuals who after their death will not be remembered for anything except for being burdens to their families and societies; however, in Finland such individuals are few because the sense of responsibility is pretty high. Especially because many have bills to attend to at the end of every month, so they work very hard to live up to them. But whereby one is unable to live up to his or her responsibilities, the Finnish welfare state has a provision for supporting such individuals (Kansaneläkelaitos – KELA, Social, and so forth). So for this participant, giving-up responsibilities probably includes abandoning her ability to be productive, and then fall into the already available safety net. Giving-up her responsibilities probably also includes continuing the act of doing drugs. Confining in me, this participant said that the drugs even led her to social vices (which I will not mention for ethical reason), and the consequence of that, coupled with testing positive to HIV did not just make her clean, but had kept her that way.

For further insight, concept maps in figures 9 and 10 in pages 75 and 76 separately map out the overall knowledge and understandings of the Finnish and Nigerian participants, and table 7 in appendix I, further illustrate the similarities and differences between the two groups` initial knowledge of HIV/AIDS in comparison with results of earlier studies. The next sub-category described participants` present understandings on HIV/AIDS.

### 4.1.3 Present understandings on HIV/AIDS

In the preceding sub-category, the initial knowledge of the participants were described and compared, in this sub-category, their transformed understandings have been described and compared too. Since change is constant, it is not surprising that change in views is inevitable once an individual tests positive to HIV, and verbally demonstrating that one of the Finnish participants said:
*Oh yeah! Obviously, once I got it, it changed dramatically (sh0485ff).*

The present understandings of the Finnish participants on HIV/AIDS are 'not necessarily a death sentence, no more as something dirty, not necessarily aids, and just a disease', while the Nigerian participants presently see the disease as, 'not necessarily a death sentence, not necessarily aids, not that scary, no more fearful, not that contagious, only a severe fever, just a disease, unnecessary struggles, and HIV vaccination uncertain'. Under the above themes, the responses of the participants have been described and compared in this subcategory.

**Not necessarily a death sentence:** Even till date many still believe that HIV/AIDS is a death sentence despite the fact that it is being herald and echoed loud and clear that the disease is not a death sentence. In contrast with one participant in Anderson and Spencer (2002) who perceives AIDS as a skeleton crying, the participants of this study no longer see it so, probably because experientially they have been convinced. A Finnish participant reflecting that this is a knowledge that she had newly and experientially acquired said:

*Now I know I won`t die of it because I have medication if I don`t start using drugs again I will probably die of old age.... (sn9975ff).*

The 'now' in her response probably indicates that the knowledge has been acquired newly, and the later part of the response reflect that if she would not start destroying her body again with illicit drugs, her body will fully recovery from previous abuses which will give her the opportunity to live till old age.

Two of the Nigerian participants who share the same view expressed it differently. One acknowledging that death sentence use to be the only thing the disease is perceived to be said that such view is changing daily:

*Initially, anyone that hears HIV just believe it mean 'death sentence', in no time this person is going to die. People`s perceptions about the disease is changing on a daily bases (tp0389fn).*

Another describing her experience upon testing positive to HIV said; the fear of dying consumed her, and she bitterly cried, but through counselling and the observation of some improvements on her health after she began to receive treatments, she became convinced that the disease is actually not a death sentence.

*Actually, that (death sentence) was what came to my mind, and I was crying, but it was through counselling I got better... I came to conclusion (that is not a death sentence) when I have seen, by the time they started giving me treatment, there was improvement (aw0071fn).*

**Not necessarily AIDS:** HIV and AIDS are often written side by side, and to many the two are the same. But though HIV may progress to AIDS, the two are not the same. A Finnish participant expressed it thus:

*Hiv is not aid, nor does it lead to aids necessarily. Hiv can be blown into fully developed aids. They are differenrt stages of the same disease…. Well nowadays if I take my medicine treat myself right maybe I`ll never maybe get AIDS (ms9367ff).*

Another Finnish participant in agreement with the first said:

*So nowadays is not usually like in the 80s you have HIV you get AIDS and die (sh0485ff).*

Then a Nigerian participant who also agrees with them said:

*...it was when I came across it [when I tested positive] I know that is different from AIDS. Is when HIV is not been care of before it leads to AIDS (as0481fn).*

According to the participants in Anderson and Spencer (2002), one still has the chance to fight while it is still HIV, but once AIDS begin to appear in one`s record, the person has bought a ticket [to death]. So it seems that, if people living with HIV (PLWH) are consistent with their medications, and care for themselves they may not have to worry about AIDS.

**Not that contagious:** PLWHA are highly discriminated and stigmatised chiefly because many believe that by doing so they are protecting themselves from becoming infected with the disease. The fear of HIV/AIDS` contagiousness remains high which is why as recent as 2009, more than 50% of Nigerians say they cannot shake hand, hug, or share the same toilet with PLWHA (Ogunjuyigbe, Adeyemi & Obiyan 2009). But according to a Nigerian participant, the trend is changing because people are becoming better informed*:*

*And if anyone is said to be HIV positive, they believe that this person, if you go near this person you will be infected. But now, the perception is changing on a daily bases, in the sense that people are actually getting more knowledge on what it is all about, how it can be contracted, how it cannot be contracted you know. HIV to me with the level of awareness now, people are not as scared as they use to be in the past. So is changing on a daily day to day bases, is changing and that really has helped improve our conception (tp0389fn).*

Then a Finnish participant who also shares the same view said:

*...now that I know that because of the medication I know that am not you know dangerous (sn9975ff).*

Luckily, there are now new medications capable of reducing the chances of getting infected with HIV, and recent studies suggest that male circumcision alone can significantly reduce the risk of contracting HIV though sex (WHO 2010b).

**Just a disease:** It may appear surprising that the views of the participants have changed to the point that some of them now see HIV/AIDS just as any other chronic disease. This view is held by participants from both group. One of the Finnish participants said she no longer sees HIV/AIDS as a mortal disease, but as a chronic and treatable one that does not lead to premature death.

*I no longer think of it as a mortal disease. It is a cronic one, treatable one ...it is a chronic disease among other diseases. It no longer leads to premature death (ms9367ff).*

Another likened it to diabetes of which if well managed the sufferer will live as normal as possible.

*It can be like a chronic disease, a bit like diabetes that some people can treat it and manage to live with it, live as normal as possible... (sh0485ff).*

A Nigerian participant in expressing similar view likened it to hypertension and diabetes.

*...is not something to me, is not something somebody will need to kill him or herself for. Is just like ordinary other diseases. Like people can manage hypertension, can manage diabetes, can manage other things, so also HIV. And I think those that have diabetes they always take their drugs. When they are down they will go to the hospital, those that have hypertension they are on drugs, the drug helps them to manage it, but it doesn't have cure! Like HIV it doesn't have cure, but you can manage it with the drug ...it was then I say this is not a do or die matter (aw0071fn).*

But another Nigerian participant sees it as a condition.

*I just see it as a condition (tp0389fn).*

Of course, the participants of this study are not alone in painting a mild picture of the disease, in Anderson and Spencer (2002, 1348) some participants made AIDS sound better by imaging it as a chronic disease like cancer or diabetes that only requires regular taking of one`s medications. One of them says: "At first I thought I was going to be all messed up, all dried up and looking weird and stuff like that, but I don't think of those things anymore. I just keep living life". In Aga, Kylmä and Nikkonen (2009) the same imagery was used to minimise the weight of HIV/AIDS.

**Sure HIV vaccine uncertain:** There is no sure vaccine or cure for HIV/AIDS (Ristola and Sutinen 2002, UNAIDS 2004). A HIV vaccination conducted by the US army in Thailand was only 31.2% successful (BBC September 2009). Recently, a 44% to 73% prevention drug (Truvada) was approved by FDA (BBC May 2012). But based on the knowledge of the participants, the hope for a sure HIV vaccine remains uncertain which was extensively expressed by a Finnish participant.

*Well, I don't know a lot about it, but I know is very hard to find it. The virus it`s, it changes so rapidly, and it look so different in people, people like have different strain of it, and also the strain you have is very, is a very intelligent virus, and also it hide in the cells that are not used so even if you get it away, if you get it away from the active cells in your body, is hiding in the not active ones. And I know that there has been some vaccination, there have been some research somewhere in Africa, and it has minimised the possibility of getting the disease 40% or something. I really think like safe sex and clean*

*needles, needles protection proper, they are the best vaccination, 40% is not, I don't think before companies come with this 100% vaccination, maybe we should put more money on information and you know helping to stop it in other ways you know* (*sn9975ff)*.

The Nigerian participants` understandings on HIV vaccine ranges from haven not heard about it to the knowledge that they are available.

*No I have not heard about it (as0481fn).*

*I have heard it but I don't know much about it (ht0484fn).*

*There are vaccines now that will help [control] the infection, like for instance I want to get married to – my partner is negative, that vaccine will help prevent my infecting him, of course I want to get pregnant (tp0389fn).*

**No more as something dirty/ No more fearful:** A Finnish participant who use to consider the disease and the people living with it as dirty including herself no longer does so. Though it took her a long time to change the view.

*Well, I thought it was somehow like you know dirty, and the people with the disease are dirty, and I considered myself very dirty as well when I first got it, and that took a long time for me to get rid of that, you know just feeling of been dirty, but that has changed, I don`t think about it in that way (sn9975ff).*

Perhaps she held on to that view for long because in the Finnish context the primary framework for understanding AIDS is gay plague (Clarke 2004); that is seeing HIV/AIDS not just as a disease but a plague or punishment for practicing wrong sexuality, but now such thoughts have almost disappeared probably because heterosexuals are more and more being represented in the community of PLWHA in Finland.

Then in Anderson and Spencer (2002) AIDS was plotted as 'a skeleton crying'. That is in agreement with the 1980s and 1990s understandings when many Nigerians thought that, once an individual gets infected with HIVAIDS, within the next few years the person will begin to lose weight which continues until the individual is reduced to skeleton, and then dies. The Nigerian media played significant role in painting this image which scared many. But recently, the disease is no more seen in that light by increasing number of Nigerians, instead it is seen as other chronic diseases; the new view is expressed by a Nigerian participant in this way:

*That was then, not any more (i.e. skeletal image). Is before, is that image that put fear into human – to people. That impression they gave that time. They just brought skeleton and everything, but now if you are walking you cannot know who is who. That impression then they created that is what has created that fear in people (aw0071fn).*

So notwithstanding that being reduced to skeleton was the primary plot for understanding HIV/AIDS in the 1980s and 1990s by many Nigerians and other Africans, it is becoming clear that those who were reduced to skeleton had other diseases, and perhaps coupled with malnutrition.

**Only a severe fever:** Malaria is very common in Nigeria, and most times it comes with severe fever. Among the Nigerian population 97% are at the risk of suffering malaria fever, which is why an estimated 100 million malaria cases are reported each year with over 300,000 deaths. Comparing that with 215,000 HIV/AIDS annual deaths shows that HIV/AIDS is lesser health care problem than malaria in Nigeria (NMFS 2011). A Nigerian participant likens the two; arguing from religious stand point said her pastor once identified HIV/AIDS as the severe fever Peter`s mother suffered[26].

> *To be candid to you, I was in church one time our pastor was saying that what we now know as HIV was actually what Peter`s mother had as severe fever in the Bible (tp0389fn).*

**Unnecessary struggles:** The imaging of HIV/AIDS as a deadly disease like "AIDS devours its victims before your very eyes AIDS" (Clarke 2004, 222) has lingered in the minds of many. A Nigerian participant who after some years of living with HIV realising that it is not so said:

> *...so luckily for me after some years, by the time I started taking my drugs and all that, I was like haa! Is it that simple? Then I was dying inside – for I feel free, I just live like a normal person, as if nothing has wrong with me. (as0481fn)*

From the above expression, the participant seems really glad that the stress she was passing through is now over because it is unnecessary; a realisation which made her to regain her life.

### 4.1.4 Summary of present understandings on HIV/AIDS

In this sub-category a total of fourteen themes (six and eight from the Finnish and the Nigerian participants respectively) emerged on the participants` present understandings of HIV/AIDS. They reveal that the present understandings of the Finnish and Nigerian participants are much better than they were prior to their being diagnosed with the disease. This is probably because they became better informed about the disease after testing positive to it, or because views on HIV/AIDS are generally getting better. So unlike the old understanding of the disease as the one that reduces an individual to skeleton and untimely death, the participants now no longer perceive the disease as a death sentence. Furthermore, unlike went the disease was solely attached to social immorality; a Finnish participant said she no longer sees herself or every other PLWHA in that light. Both group also said HIV is not necessarily AIDS because through medications and healthful living, HIV may not progress into AIDS. They also no longer see themselves that contagious.

Since they no longer see the disease as a death sentence, their fear of it had also reduced significantly even to the point that they now see it as any other

[26] Mathew 8:14, Mark 1:30, Luke 4:38

chronic disease, and a Nigerian participant through the conviction of her pastor said it is the same as the severe fever Peter`s mother suffered in the Bible. Another who struggled with her HIV-positive status for few years said from the way she now sees the disease, her struggle was needless and uncalled for, if she had known what she does now. But to both group finding a perfect HIV vaccine seems uncertain. Therefore, the perceptions of both group on the disease is much better than it was.

For further insight, concept maps in figures 9 and 10 in pages 75 and 76 separately maps out the overall knowledge and understandings of the Finnish and Nigerian participants. Then table 8 in appendix I further shade light on the participants` present understandings on HIV/AIDS in comparison with findings of earlier studies. The next sub-category briefly examined the participants` knowledge on the origin of the disease.

### 4.1.5 The origins of HIV/AIDS

Though AIDS was discovered in 1981 (MMWR 1981), and HIV in 1983, the origin of HIV/AIDS remains shrouded in mystery. Investigating the origin of the disease may be of little importance to this study; however, it was explored because it may have influence on the way the participants accept and live with the disease. In this sub-category, the few responses of the Finnish participants are described under two themes, namely: 'a virus that existed in the Tropics, and maybe from Monkeys'. While that of the Nigerian participants are described under four themes, which are: 'from time immemorial, a foreign illness from the Western World, a disease from God, and unimportant'.

**A virus that existed in the tropics/ From time immemorial:** A Finnish participant said the disease had always existed in the tropics.

*It must be a virus that has always existed i the tropic (ms9367ff).*

It is unclear why she believes that, but the tropics being the region of the earth surrounding the equator (warmest parts of the world) which harbours about half of the world`s population, it seems part of the reason why she believes that is because the warmth and congestion of people around the region encourages the spread of infectious diseases. But to pin-point a particular place, she further said that it existed in Ancient Egypt.

*Something like this existed allready in the anchient Egypt (ms9367ff).*

Egypt is located around the northern most end of the tropic, and since some scholars argue that she has early civilisation, perhaps she is right. But a Nigerian participant whose view somewhat differs said the disease existed before Jesus, even from time immemorial.

*HIV has been even before Christ. So I will say it has being in the system from time immemorial (tp0389fn).*

Going by the later view, the disease's origin remains shrouded in mystery.

**Maybe from monkeys/ A disease from God:** A Finnish participant who acknowledges that a disease similar to HIV has been found in monkeys is not sure HIV really came from monkeys.

> *I know that they have found in some monkeys disease very close to it, if not the same but they don`t know if – that is the way it came to you know humans, maybe is from monkey, but it was something – I know they have started researching it. New York, I think in the 80s where a lot of homosexuals died of this disease, that was fast accumulating (sn9975ff).*

In agreement with this participant, the theory that HIV might have come from monkeys is questioned by some scientists who argue that HIV in humans and SIV (Simian Immunodeficiency Virus) in monkeys are not compactable (Kirchhoff et al. 2008). But a Nigerian participant has a completely different view on where the disease came from. Taking her stand from the Quran, she said God deliberately sent it as an incurable disease without which the fear of God would have been much more wanting.

> *The all I know is that everything is from God, because is written in the Holy Quran that "there will be a time that I will send emm, I will send a problem that you will never find a solution to it – to the world", and I know this is what, this is going on now. God has send a problem when we are searching for solution you can`t find. If it has not happened there won`t be God fearing, people will not fear God, so let me say everything is from God (as0481fn).*

Of course, her view is in agreement with that of those who see the disease as a plague which emerged as a result of immoral lifestyles.

**A foreign illness from the Western World:** Then another Nigerian participant said that the generally believe is that the disease is of foreign origin, pinpointing a place she said the disease came from the western world to Africa through expatriates.

> *We do believe that, general believe is that HIV actually came from our expatriates. Okay? Those who were exported abroad, taken in form of slavery and all of that, and they were brought back. So the general believe is actually HIV is a foreign illness brought from abroad, from the western world (tp0389fn).*

**Unimportant:** Yet another Nigerian participant said while some argue that, it came from homosexuals in the US, and others argue that it is from monkey in Africa, to her it is unnecessary to hunt for the disease`s origins. Metaphorising it as a 'burning fire' she argues that, the most important thing is to extinguish it rather than searching for its origins.

> *There are so many history, one say is gay from America, one say a monkey in Africa, but for me there is no need, am looking farer than that. If you find a fire burning what will you do? (ht0484fn)*

### 4.1.6 Summary of the origins of HIV/AIDS

In this sub-category a total of six themes (two and four from the Finnish and the Nigerian participants respectively) emerged on the origins of HIV/AIDS. The themes show that while a Finnish participant views HIV/AIDS as a disease that has always existed in the tropics (Egypt in particular) which probably might have come from monkeys, her Nigerian counterpart through the conviction of her pastor believes that it is the same as severe fever and had existed from time immemorial. Another Nigerian participant sees it as a disease that had come from God which is aimed at restoring His fear in humans. Yet another Nigerian participant pinpoints it as a foreign illness which came from the Western World to Africa through expatriates, and the fourth Nigerian participant thinks that it is unnecessary to search here or there for the disease`s origin, instead all hand should be on desk in search for a more permanent solution.

From the responses of the Nigerian participants, one could easily see their fundamentalist views and influences of religious beliefs (Christianity and Islam) unlike their liberal Finnish counterparts. For further insight, concept maps in figures 9 and 10 in pages 75 and 76 separately maps out the overall knowledge and understandings of the Finnish and Nigerian participants, and table 9 in appendix I further illustrates the understandings of the participants on the origin of HIV/AIDS in comparison with findings of earlier studies. The next sub-category explores the negative sides of the disease.

### 4.1.7 The negative sides of HIV/AIDS

There are both negative and positive sides of HIV/AIDS, and in this sub-category the negative ones are explored. From the Finnish participants, the negative side themes are: 'stigma of shame, something black, red, white and round, limited lifespan, fast spreading disease, linked to gay sex, iv-drugs and promiscuity, a stamp of self-inflicted disease, stigmatisation due to few PLWHA in Finland, constant reminder of death, people suffering and dying, restricted travelling, and always the criminal'. While to the Nigerian participants, the disease`s negative sides are: 'negative labelling and a disease that affects one mentally'.

**Stigma of shame/ Negative labelling:** As tuberculosis and cancer were mythologized in the 19$^{th}$ and 20$^{th}$ centuries respectively, towards the end of the 20$^{th}$ century AIDS was mythologized as the punishment for sexual or social deviance (Clarke 2004). As such, a HIV-positive woman (Gugu Dhlamini) was stoned to death in 1998 by men in her community in South Africa after declaring her HIV-positive status on radio and television (UN 2007). This may be similar to 'honour killings' that happens in Arab countries[27]. Probably the men who did the horrible act felt that they cannot bear the shame brought upon their community by the woman, so thought the best thing was to squeeze life out of her in cold blood. The same stigma of shame was identified by a Finnish partic-

[27] Recently, there have been reports of honour killings also happening in the western world (Yle May 2012)

ipant who also believes that the disease is socially restricting. However, the good news based on her response is that the trend is changing.

*Unfortunately it has got a stigma of shame and it is socially restricting. Not so much anymore, attitudes are chancing.... The social and spiritual stigma should be lifted (ms9367ff).*

A Nigerian participant who also acknowledged such stigma of shame called it 'negative labelling'. It worries her that the PLWHA are often seen as individuals who flirt a lot while as she remained a virgin until she got married. So, she has been working very hard to correct the impression through telling her story.

*…all that they believe is only through sexual intercourse – that is their own! And I told them I never flirt around, I was a virgin when my husband got married to me (as0481fn).*

**Something black, red, white, and round/ A disease that affects one mentally:** In Anderson and Spencer (2002, 1348), one participant while painting a picture of AIDS drew a wide vertical line beginning at the top with the first phase – diagnosis, coloured red meaning things are not good. The phase that followed was shaded blue and labelled 'medication, education, and acceptance' to reflect the sky that he could see from his inpatient bed. Then the final stage was coloured bright yellow and labelled 'hope'. Similarly, a Finnish participant using colours to describe the disease said it means:

*Something black and red, black like the stigma, death. Part of the red is the blood, is also very powerful. And maybe it would be like round thing with black, red, and white, because it has all that included, it has life, death, everything included in it (sn9975ff).*

To have come up with the black, red, and white colours she used in describing the disease, some number of brain storming would have taken place in her mind, and this reflects the kind of mental and emotional stress that HIV/AIDS brings upon PLWHA. This may also be the reason why a Nigerian participant said if one allows it, HIV/AIDS may affect the individual mentally even to the point that he/ she may not be able to communicate well.

*...some time HIV if you let it affect you, it will affect you mentally, yeah you cannot do anything actually not only in education, cannot cannot even communicate (ht0484fn).*

**Limited lifespan:** It seems people do not often appreciate their life until they discover that they are about to lose it. As such, right from the early 1980s when HIV/AIDS was discovered, the disease has always been projected as a life devourer, which is why once an individual tests positive to it, the image that comes to the individual`s mind is sickness and death (Anderson and Spencer 2002). Similarly, two of the Finnish participants, upon testing positive to HIV in 1993 and 1999 respectively were told by their physicians that they have limited time to live. One was given about 10 years and the other 10 to 15 year, which they testified thus:

*The doctor then proceeded telling me I had about 10 years to live (ms9367ff).*

*When I got it in 1999, I was told I will live maybe 10 or 15 years (sn9975ff).*

But fortunately, the two are still alive and well, though they have lived with the disease for twenty years and fourteen years respectively. Of course this may means that with proper medications and healthy lifestyle one may still bit the doctors` predictions on life expectancy after testing positive to HIV/AIDS. Furthermore, the third Finnish participant said that though life expectancy remains high in Finland after testing HIV-positive due to functional health care system and other privileges in Finland, but in other places testing positive to the same disease could mean a death sentence due to poor health care.

*In some country I think that the truth is like your life expectancy isn`t so rosy with the disease. But in Finland is kind like everything works just fine (sh0485ff).*

**Fast spreading disease:** Another negative side of HIV/AIDS to a Finnish participant is that it is a fast spreading disease. She sees easier, cheaper, and faster travelling as the factor responsible for that.

*...but ionly started to spread more videly when tavelling was made easier, cheaper and faster (ms9367ff).*

Of course, her argument sounds reasonable; sexual contacts which in many occasions accompany migration and tourism facilitates the spread of HIV/AIDS (Clarke 2004). In 1981, AIDS was discovered in only five gay men in Los Angeles (MMWR 1981), and just in about three decades it has circulated the globe with about 33.4 million carriers worldwide. But the fact remains that it is not the fastest spreading disease in the world; but the speed at which it is spreading is often acknowledged because of the disease`s exceptionality, and to really tame the spread, as a duty the sense of personal responsibility is required from all.

**Linked to gay sex, iv-drugs and promiscuity**: In the 1980s the predominant plot for identifying AIDS in Finland was gay plague (Clarke 2004). Later it became also linked to IV drug usage, and promiscuity all of which are socially distasteful. But are all the PLWHA gays, drug users, or promiscuous individuals? Of course not, this is the reason why PLWHA who do not belong to any of these groups see being HIV-positive as the cause for their identity crisis, and a Finnish participant who feels concerned voiced it out thus:

*It is linked to gay sex and iv- drugs and promiscuiety (ms9367ff).*

**A stamp of self infliction:** Furthermore, because of the disease`s link to immorality and promiscuous sex, many due to lack of knowledge or limitation of it see the disease as nothing more than a self-inflicted plague, some even go extra miles in stigmatising PLWHA. For example, in Cao et al. (2006) study of 601 female migrants in Shanghai, 54.6% of the respondents believe that those who acquired HIV through sex and drug use deserve it. But the one million dollar question is – how can those who acquired the disease through promiscuous sex, drug abuse, and other socially classed immoral acts be known or singled out? This is of course a mission impossible, and as such the PLWHA are generally

seen as those who inflicted the disease upon themselves. A Finnish participant expressed the pain in her heart due to the disease`s classification as a self-inflicted one which is why PLWHA receive no sympathy or support like those living with cancer some of which are obviously self-inflicted. In her agony she said:

> *It has a 'stamp' of being a self a self- inflicted sikcness. So in fact are many other diseases but they do not carry such a stigma. People suffering from cncer etc get a lot of symphaty and support even though most of the cancers can be self afflicted too. And cancer of cervix has also beeb proved to have started from papilloma- virus spread by sex (ms9367ff).*

**Stigmatisation due to few PLWHA in Finland:** The overall HIV/AIDS statistics in Finland and Nigeria are 2600 and 3,300,000 respectively (UNAIDS 2011), and based on the UNAIDS/WHO (2008) global HIV/AIDS epidemiological fact sheet[28], HIV prevalence among young Finns and Nigerians (aged 15–24) are respectively 0.1% (male 0.1%, female <0.1%), and 1.6% (male 0.8%, female 2.3%). So compared to Nigerian and many other countries, the PLWHA in Finland are relatively few. As such, though all the PLWHA suffer discrimination and stigmatisation in one way or another, a Finnish participant believes that the PLWHA in Finland are much more prone to it because they are only few.

> *...the biggest issue about this disease is stigma.... Is a big issue in Finland there are not that many is not like everyone know someone who has it, or if they do, they probably don`t know they have it... I think the stigma is – I don`t know if it will ever ever change or maybe slowly, you know people use to think about epilepsy is something terrible – it was very stigmatised ... I think it makes people not to go and test themselves, which is the worst thing to do, I think I think that stigma make people afraid of – they don't wanna know, they just don't wanna know (sn9975ff).*

Due to the limited number of PLWHA in Finland, the above participant thinks that the end of HIV/AIDS stigmatisation in Finland is still far away, but her only hope that the stigma will end someday is that epilepsy was once that stigmatised but today that has changed. But to her, the greatest danger the stigmatisation imposes is that it scare people away from getting tested. Adding her voice to the issue of HIV/AIDS stigmatisation, another Finnish participant pitched her hope for change on the fact that people cannot be that stupid forever.

> *I think they have to [change] because people in general can`t be that stupid their whole life, I think at some point they will see it as any other disease like any other. I don`t know how long is going to take, but is gonna take hard work. I don`t think that people will carry on being ignorant for 10s and 10s of years (sh0485ff).*

[28] http://apps.who.int/GlobalAtlas/predefinedReports/EFS2008/index.asp

**Constant reminder of death:** HIV/AIDS is seen by many as a constant reminder of inevitable death. Anderson, Ryan, Brown and Gray (1999) attested that testing positive to HIV/AIDS is like receiving an emblem of death. In Anderson and Spencer (2002, 1347-8) a 29-year-old woman drew a picture of a grave with delicate red and yellow flowers and wrote on the tomb stone 'RIP Devoted Sister and Daughter'. Over the grave, she drew a black cloud with the sun peeking around the edge and described it as symbolising her family's sadness at her death. A Finnish participant who expressed similar view says that taking her pills everyday reminds her of something, and though one will definitely die at some point, living with HIV glitters it on her face.

*...obviously someone die at some point but when you get some reminder that you are going to die at some point, then it can like put new perspective ...when I take my pills, I remember that there is something why I have to take them (sh0485ff).*

**People suffering and dying:** As confirmed by Awa and Yamashita (2008), there are physical, mental and socio-economic health implications of HIV/AIDS. But demographically, the suffering and dying due to HIV/AIDS differs from place to place. In the sub-Sahara Africa and other less privileged parts of the globe, the disease worsens the existing health problems due to malnutrition and lack of proper health care. One Finnish participant thinks that it is unfair that she and other PLWHA in Finland and other privileged countries are gracefully coping with the disease while as hundreds of others are suffering and dying because they lack similar privileges.

*...is really wrong that am doing well with drugs, there is 100s of people out there suffering and dying and they don`t get the same opportunity (sh0485ff).*

**Restricted travelling:** Even till date, many countries still have some forms of travel ban on PLWHA. In the 1980s, it was a requirement for many foreign students to take HIV tests before entering Finland (Clarke 2004). The US has recently lifted the travel ban on HIV/AIDS (CDC 2009), and China did the same shortly before hosting the Olympic Games in 2008 (Yuanfeng and Ying 2010). A Finnish participant who expressed her dissatisfaction with the travel bans said:

*...we should be allowed to travel to every country. Some countries still have restrictions (ms9367ff).*

**Always the criminal:** Legal scholars argue that criminal laws on HIV are exceptional in the sense that they are enough to prove that the accused has engaged in forbidden acts. This makes it appear as though safe sex is the sole responsibility of PLWHA (Clarke 2004). All the Finnish participants extensively expressed their dissatisfaction with the implementation of HIV laws in Finland, and advocate for a review on the laws that permanently portray the HIV-positive individuals as the criminals and the HIV-negative ones as the victims. One of the Finnish participants told the story of how her friend was affected.

*I don't know if is practice still, but I know this really this friend of my she died of drugs she was young girl, woman she died few years ago but she was*

*very very young when she got this disease, she was using drugs and she had really hard life, and I think she was maybe 19 years old at the time, and she went to this bar and this probably 30, 40 years old man who work at the bar probably seduced her and took her home and went to bed with her and then afterwards he found out that she is HIV-positive, he sued her for not tell him, and she got a fine she had to pay and in that really that case because I know my friend I know the story emm I really think she was the victim, because she was seduced, so (sn9975ff).*

Another Finnish participant similarly said:

*Now if someone has sex with a hiv positive person , that other one can practically start accusing the positive one of a crime. Sex is always a deal of two. Both sides should take the responsability. Take for example the case of that african prostitute. She was selling sex, the men bought it knowing she was a pro. Yet they did not use a condom. When they learned she was posituve , they sewed her. Weere they not responsable for their actions Who does it with a pro unprotected? Even though no- one was infected and she claimed to have used female condom, she was sentenced to prison, her photo and name published in a newspaper. Witchhunt eh? Those guys who bought sex, which in fact in opressing and abusing of a woman were so called" victims". This law should be changed (ms9367ff).*

The third Finnish participant also similarly said:

*Obviously there have been some people who has been doing it on purpose to get someone else infected, but there is also people who really don`t mean it and accident happen....Well, I haven`t really, am not quite sure like how the law different between different countries, but in Finland I will like the law to be more clear, like because is kind of like grey area if you infect someone, and someone prosecute like what is happening, so is kind of, there should be like basic rule like some protection for HIV-positive people like, am not sure how in Finland it goes what actually happens if someone. Yeah, I think like more especially like HIV-positive people should have more protection law wise, and otherwise like right. I think that is really difficult. Okay like if you don`t use condom, I don`t is just weird that it can be said that the saying like you attempt to like murder someone, so in the laws well I thinks that`s a bit, oh yeah, you are not with a gun somewhere, so I think like it be a bit more easier, especially if you haven`t really meant to do any harm, okay, if you actually wanted to infect many people then is bad, and like it varied like in Finland, Sweden, Norway, Denmark, I don`t know how the law works, but I have heard that like even though we are close, the laws is kind of different in every country like some country is better some worse, there should be like more like worldwide consensus like what is happening (sh0485ff).*

### 4.1.8 Summary of the negative sides of HIV/AIDS

In this sub-category a total of 13 themes (11 and 2 from the Finnish and the Nigerian participants respectively) emerged. The themes reveal that the Finnish

participants are much more vocal than their Nigerian counterparts in expressing their views on the negative sides of the disease. So while only 2 themes emerged from the responses of the Nigerian participants, 11 emerged from their Finnish counterparts. This could either be because they have experienced more of the negative impacts of the disease than their Nigerian counterparts, or that they were just more vocal (as illustrated in figure 8 below).

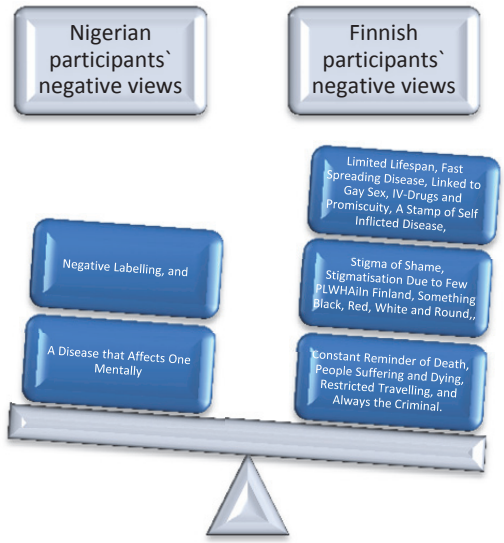


**Figure 8.** Gaps in the Finnish and Nigerian participants` negative views

For further insight, concept maps in figures 9 and 10 in pages 75 and 76 separately maps the overall knowledge and understandings of the Finnish and Nigerian participants, and table 10 in appendix I shows the comparison of the two with findings of earlier studies. The next sub-category examined the participants` views on the positive sides of HIV/AIDS.

### 4.1.9 The positive sides of HIV/AIDS

Although there are many negative sides of HIV/AIDS, there are positive ones too. In this sub-category, the positive sides have been explored and described based on the responses of the participants of this study. The themes that emerged from the Finnish participants are: 'not a death sentence, life restorer, one more reason not to start using drugs again, and HIV-negative children'. While from their Nigerian counterparts, the themes that emerged are: 'healthier than those who are not sick, saving a sister's life, an encouragement for fidelity, HIV-negative children and normal life'.

**Not a death sentence/ Healthier than those who are not sick:** as the three decade old debate on hiv/aids being a death sentence or not ranges on, it may be surprise that the study of Fryback and Reinert (1999) reveal that cancer and HIV/AIDS patients who are positive about their disease report better quality of

life than before they were diagnosed with their diseases. One Finnish participant who is positive about her HIV-positive status said she personally does not see the disease as a death sentence, and hopes that she will live till old age. However, she acknowledges that it is not the same for all the PLWHA.

*No, for me I don`t think, but in the world there are so many people dying... somewhere else is basically a death sentence but to me is a bit like a chronic disease, in here everything is so good... I hope I will die of old age I can`t be 100% such of what is going to happen but am feeling positive about it (sh0485ff).*

Her Nigerian counterpart whose expression is similar said, by taking her medications and proper nutrition, she feels that she is now healthier than those who are HIV/AIDS free, and she may only die after she has become very old.

*...right now I know that people with HIV can live and live and live till they got old, nothing is in HIV... is not a deadly disease... taking your drugs normally, eat food very well, you will live healthy more than those who do not have anything (as0481fn).*

**Life restorer/ Saving a sister's life:** Undoubtedly**,** HIV/AIDS draws the attentions of PLWHA to their health. Through the use of medications PLWHA are kept well and productive for a long time (WHO 2010b). Though it sounds contradictory, to one Finnish participant who was a drug addict, testing positive to HIV restored her life when she thought she was dying in a strange way.

*I have thought about the disease a lot in some way I think maybe you know is quite like a paradox, but and I found out that I have the disease and started thinking about it, and when I thought that I was dying in some strange way it gave back this life to me (sn9975ff).*

To another Finnish participant, while the disease has not made her healthier, it has been keeping her healthy at least.

*In a way it have been keeping me healthy, but I don`t, am not healthier than before (sh0485ff).*

But for one of the Nigerian participants, testing positive to HIV helped her to save her sister`s life. The experience she expressed through this short story.

*Like me through me I saved one of my sister, and she is very active to work now. If you see her she is normal now. She was down, it was that year 2001. It was very, we don't know what was wrong, she was staying at (name of the place withheld), I heard that she was sick, they took her from one hospital to another, to the extent her husband took her back to where – in the village. There if they want to give her food, they pass it through the door. My sister went there and carried her, brought her to (name of the place withheld). It was then after running the whole test, then the awareness wasn't like this o! So she called me, see what is happening, I said aunty it might be this thing, already they have taken her to one traditional this thing. She was stooling (purging), if you see her fat someone she has turn to. Her stooling was uncontrollable; they were just waiting at the day she will die. Immediately I*

*heard it with the experience I have here then, the drug they gave me when I was stooling, immediately I just took all the leaf-let all the education I have gotten from lectures, I just put it inside and went back to (name withheld). I spent a month, immediately we I got to (withheld), I wrote the drugs out we went to the pharmacy and, the man that was treating her didn't know what was happening, the only thing when he gives his concussion in the morning, we took it aside, we use the one I have given, so with the drugs we were able to control the stooling. But after then I said let us try this one (anti retroviral drugs), then the drug was very scarce, they were selling it 25 thousand (naira) then. I told my aunty what are we going to do? My own they use to give me free, but I don't know for another person and she is not here (Lagos), she is at (withheld), then she gave me some money, I came down to Lagos here, I bought the drugs, when I bought it I have to send it through courier that was what I was doing until she got better. So the something, the virus, I keep on telling people, if you choose to live is in your hand (aw0071fn).*

**One more reason not to start using drugs again/ An encouragement for fidelity:** Since drugs are addictive, fleeing from them is the best option. But for one Finnish participant who was once a drug addict, testing positive to HIV is what saved her life, and it has continued to serve as her life guide and a reason not to go back to drugs.

*But is also a sought of like like a life guide, one more life guide, one more reason not to start using [drugs]. So in a way the disease sought of take cares of me, because it does take care of my health (sn9975ff).*

But two of the Nigerian participants who see the disease to be useful in our world today, see the usefulness from another dimension. In their views it attempts to limit flirting in a sexualised and promiscuous world encouraging individuals to stay faithful to their partners.

*...it encourage people to be faithful to their partners (tp0389fn).*

*Even at the age of it, some people still flirt around, but it has reduced it, it has reduced it unlike before. If you actually want, like now am positive, I cannot say I want to go and flirt, maybe if somebody else I don't know your status, I don't know whether you are positive, so whereby as a woman and a man you are positive and I am positive you sleep with me, and have sex with me, the police inside me (CD4 Cells), maybe your own virus may be different from my own, it becomes a problem for me for my drugs to work for me (aw0071fn).*

**HIV-negative children:** Since the early days of HIV/AIDS pandemic, people who have responded well to treatments have been able to pursue careers, raise families, and live healthy life (Clarke 2004). For many couples who are living with HIV/AIDS, their privilege of giving birth to HIV-negative children have not been taken away as attested by two Finnish and three Nigerian participants who have had kids after testing positive to HIV. So a Nigerian participant said she sees no danger in PLWHA marrying each other.

*There is nothing wrong in marrying themselves. When they get married they will have a child that is negative, they will have a negative child (as0481fn).*

**Normal life:** Certainly, living with HIV/AIDS affect individuals` chances of living normal life (Koopman et al. 2000). It strikes notes on one`s original routine, and many find themselves kicked off balance, however, there are exceptions. Those who are positive about their fate experience better quality of life (Fryback and Reinert 1999). One of the Nigerian participant attests that for some their living conditions are improved through positive living alone.

*Some people are living healthy, positively now and they are not on drug (aw0071fn).*

Another Nigerian participant drawining inference from eating sees herself as an example of those who still enjoys normal life despite living with HIV.

*I thank God no sickness has made me not to eat, I will never come across a sickness that will never make me to eat (as0481fn).*

### 4.1.10 Summary of the positive sides of HIV/AIDS

In this sub-category a total of 9 themes (4 and 5 from the Finnish and the Nigerian participants respectively) emerged. Except for one (normal life), each theme emerging from the Finns is somewhat similar to that of the Nigerians They show that indeed there are many positive sides of HIV/AIDS although the negative ones appear obvious. As a reverse of the last sub-category where 9 and 2 themes respectively emerged from the Finnish and Nigerian participants` responses on the negative sides of HIV/AIDS unlike the 4 and 5 in this sub-category. Based on these two sub-categories, it seems that the PLWHA in Finland conceive the disease much more negatively than positively unlike their Nigerian counterparts who conceive it otherwise. Perhaps environmental factors influenced the outcome.

Communicating recently with a Finn who occasionally suffers depression, I was made to understand that many Finns born between November and February often suffer depression due to the lack of sunlight during the period. So since the argument is somewhat scientific (Ana et al. 2006), the PLWHA in Nigeria where the sun shines almost all year round unlike their Finnish counterparts are more at advantage in coping with gloomy feelings. This abundant sunshine might have contributed to why a survey of 65 countries revealed that Nigerians are the happiest people on earth (New Scientist 2003). Nevertheless, this environmental advantage may not give all the answers for the wide gap in the conceptions of the two groups, and only a further study will provide a more authentic reason for the gap.

For further insight, concept maps in figures 9 and 10 below separately give the overview of the five sub-categories under knowledge and understandings of the Finnish and Nigerian participants on HIV/AIDS respectively. Then table 11 in the appendix I compares the responses of the two groups on the positive sides of the disease, and the comparison was backed with findings from earlier studies. This is the end of category one, it consists of 5 sub-categories and 51

themes (29 and 22 on the Finnish and the Nigerian participants` conceptions respectively), the second category explored the mental/ emotional health impacts of living with HIV.

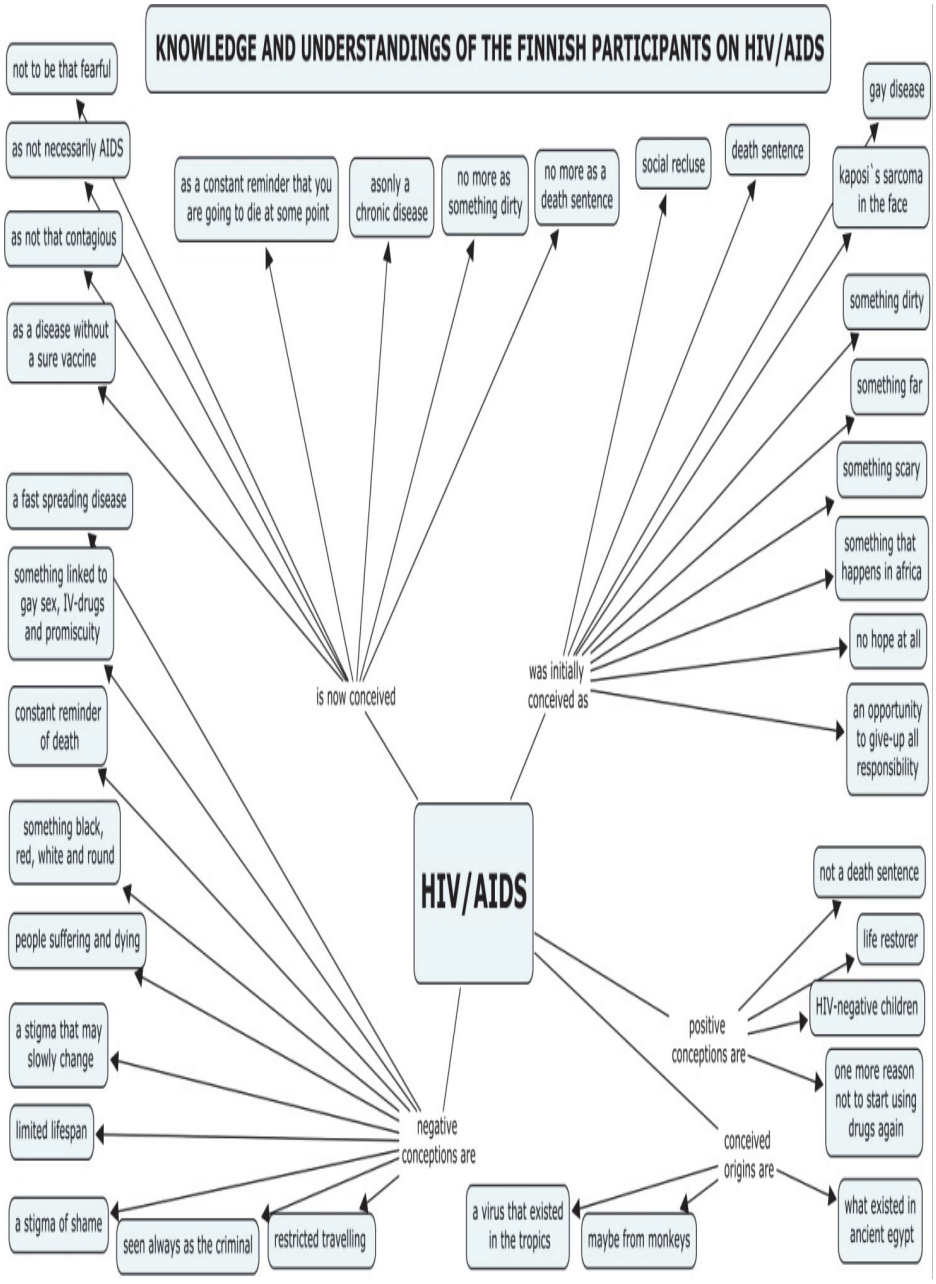


**Figure 9.** Concept Map on the HIV/AIDS knowledge and understandings of the Finnish participants

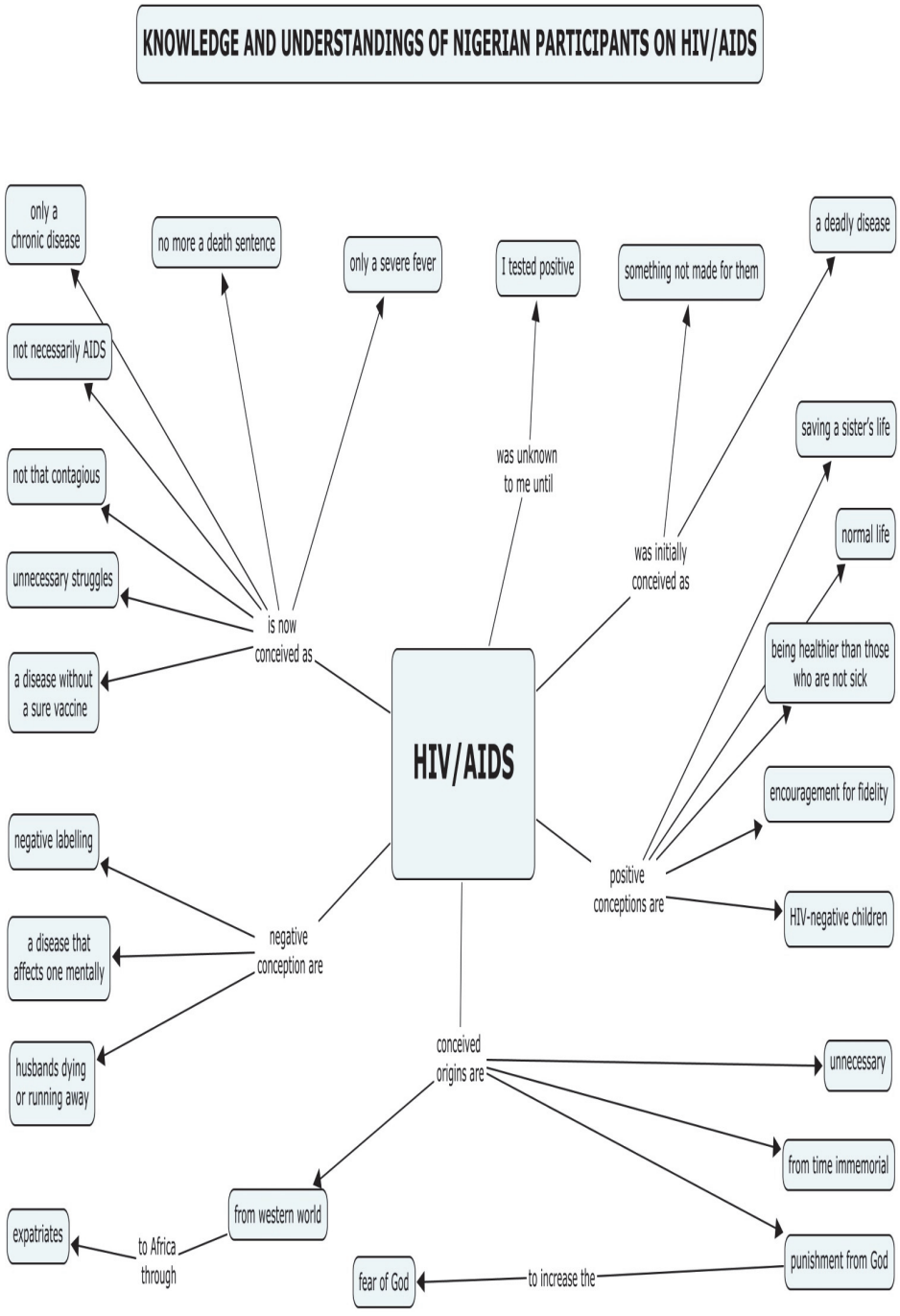


**Figure 10.** Concept Map on the HIV/AIDS knowledge and understandings of the Nigerian participants

## 4.2 Impacts of HIV on emotional/ mental health

HIV/AIDS impacts on health seems broad, but following the WHO` s definition of health (… a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity[29]), I analysed the participants` responses on the health impacts of HIV under three categories namely: 'Impacts of HIV on emotional/ mental health, Impacts of HIV on physical health, and Impacts of HIV on social health'. But in expanding the mental health impacts here, I included emotional health impacts in this analysis, and the two are described and compared under this category, while the other two are separately analysed in categories three and four respectively. While the first category is aimed at exploring the conceptual thoughts of the participants, the second till the seventh categories` explorations are primarily on the participants` immediate experiences.

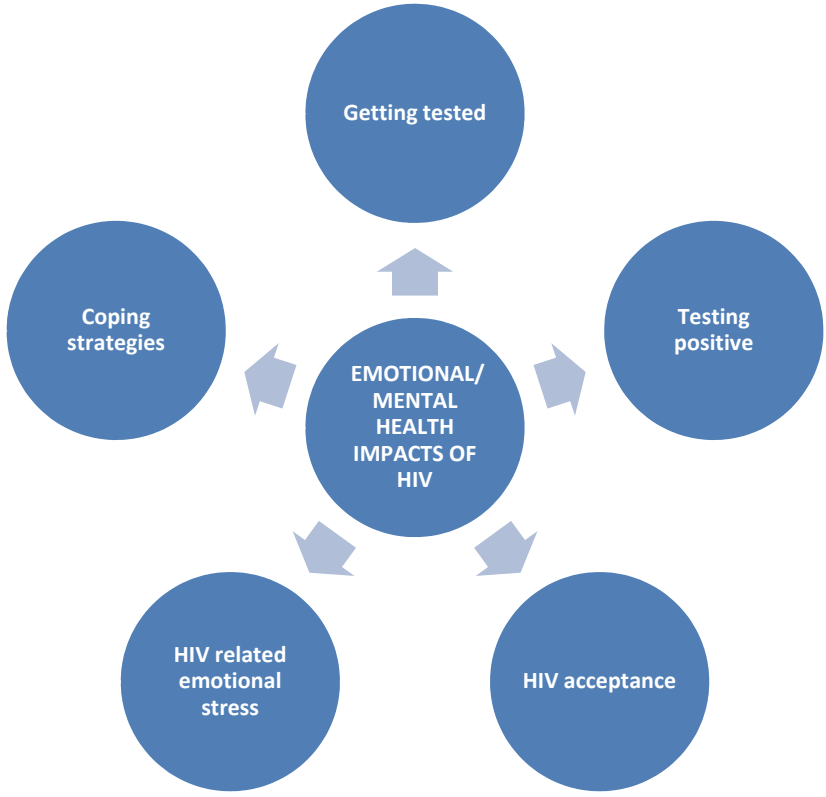


**Figure 11.** The impacts of HIV emotional/ mental health

[29] Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948. Retrieved June 24th, 2013 from http://www.who.int/about/definition/en/print.html

### 4.2.1 Getting tested

Due to fear and unpreparedness for the unpalatable news – you tested HIV-positive! Many have not gone for HIV screening or have the plan for it. Nevertheless, in Nigeria, many of the PLWHA tested positive to the disease when they went to hospital to receive treatments for a sickness (Ogunjuyigbe, Adeyemi & Obiyan 2009), and during antenatal care. For the seven participants of this study, three tested positive to HIV through maternities, two through diagnostic laboratories, and one apiece through needle exchange centre and sexual health clinic. Though it was to each of them a bitter experience, they hardly regret it, instead they encourage others to go for the screening as soon as possible because it pays to know about one`s positive status early enough when most damages are not yet done. In this sub-category one theme emerged from the Finnish group – 'worth discovering early', and three emerged from the Nigerians, namely: 'get tested on time', 'frequent screening', and 'an opportunity to start fighting it early'.

**Worth discovering early/ Get tested on time:** There is no doubt that HIV/AIDS like many other diseases especially the chronic ones should be discovered early. One Finnish participant believes that the early discovery of HIV will prevent the infected individual from spreading it further, and also the opportunity to start treatments early.

> *It is better to find it out earlier to prevent it from spreading further and to start treating it as early as possible (ms9367ff).*

Another Finnish participant who shares the same said it pays to know early when the major damages are not yet done. She is still amazed that many of her friends had refused to go for the screening after seeing what happened to her.

> *Well, obviously then the damages, the major ones haven`t happened yet because it progresses over the years, so if I found out in 10 years, I might find out when I have AIDS so that will be catastrophical compared to the fact that I found out maybe like half months the time limit when I got it.... If you wait some years you don`t know what the virus want to do with your body so I think everyone should know as early as possible.... And I have many friends that still don`t haven`t gone tested even though they know what happened to me (sh0485ff).*

A Nigerian participant who also supports getting tested on time using herself as an example said she would not have started using medications by now if she had found out that she is positive early enough, because she would have been eating the proper food for health.

> *...is very very good to find out one`s status earlier, because if I have found out earlier, maybe I wouldn't have been on drugs by now, maybe I will be eating good food. I already I have known that I have the virus, I would not allow it to bring me down. So I will know how to keep myself, is because I did not go, I did not go to find out my status, that is why the virus was able to bring me down (aw0071fn).*

Going by the later argument, must one wait until after being diagnosed with HIV/AIDS or other chronic diseases before the individual will start taking good care of his or her body? Of course not, but unfortunately, that is the routine many chose to follow, and to further worsen their situations, many still ignore the call for early discovery of their HIV-positive status in order to enable taking necessary steps for prolonging their life and avoiding spreading the disease to others (WHO 2010b).

**Frequent screening:** A Nigerian participant who suspected that she might get infected with HIV due to the kind of friends she was keeping said she use to go for screening every six months, and had continued the trend until the last screening where her result turned positive.

*I use to go to the hospital every six six months to test myself. I was tested negative before the last time I now tested positive..., then I was so scared because of the friends I was going out with, I thought I could have it and all that, but later on when they brought the result, luckily for me I was negative (as0481fn).*

Perhaps she was able to summon such courage because she had overcome the fear of being pronounced – positive. Everyone may not have such a lion heart, but it pays to summon the necessary courage to get tested once in a while.

**An opportunity to start fighting it early:** In a study of 3,556 British men and women diagnosed with AIDS, 49% of them learned that they were infected with HIV just nine months or less before they were diagnosis with AIDS (Porter, Wall and Evans 1993). If many of the participants of the above study had gone for their screening earlier, perhaps their cases would have been different. In line with this argument, one Nigerian participant strongly campaigns that individuals should explore their chances of fighting back against the negative impacts of HIV through knowing their positive status early.

*...knowing status early I will say is a good one, in the sense that it gives you the opportunity to start to fight it early... knowing early will give you the drive to try to fight it (tp0389fn).*

### 4.2.2 Summary of conceptions on getting tested

A total of four themes emerged (one and three from the Finnish and the Nigerian participants respectively) in this sub-category. The two groups share the view that getting tested on time is essential, because it will give those who test positive the better opportunity they need in carrying out a strong fight against the disease and its negative impacts. A Nigerian participant went extra miles by going for screening every six months; a trend she continued until she finally tested positive. But despite all the emphasis on the importance of finding out one`s positive status early, the fear of been pronounced 'HIV-positive' still scare many away from being screened.

For further insight, concept maps in figures 13 and 14 in pages 101 and 102 separately mapped out the overall emotional/ mental health impacts of HIV on

the Finnish and Nigerian participants, and table 12 in appendix II shows the comparison between the Finnish and Nigerian participants` conceptions on going for HIV screening. The comparison is also backed with findings from earlier studies. The next sub-category explored the meanings of testing positive to HIV as experienced by the participants.

### 4.2.3 Testing positive

The diagnostic stories of the participants of this study differ one from another as illustrated in chapter three under 'The Study Subjects'. However, one thing common in their experiences is that their lives were never the same after testing positive to HIV; probably because once a person is pronounced HIV-positive, so many things begin take place in the individual`s mind. The first reaction for many is expressions of disappointment that includes: agony, grief, despair, and so forth. As it has been explored in this sub-category, testing positive to HIV and living with the disease mean the following to the Finnish participants: 'bad news made worse, additional sorrow, this is it, being hurt, no big deal, undisclosable big dark cloud, self pity and drinking, limited social life, and recovering from lousiness. While to the Nigerian participants it means: 'you came with somebody? crying, crying, crying, the end, being ill treated, and unscarred.

**Bad news made worse/ You came with somebody?** During a HIV screening, the condition of one Finnish participant was made worse by the attitude of the doctor (in another EU country) who told her about her positive result.

> *I was 8 months pregnant by then. All this time, the doctor did not even offer me a chair where to sit while listening the bad news (ms9367ff).*

Though the ethical practices of some medical practitioners are questionable, many still uphold theirs, which is why when one of the Nigerian participants went for her diagnosis, when the medical practitioners who was supposed to break the bad news to her saw that she was very sick and may not withstand the news, the practitioner asked her if she came with someone. Although such question still sends the signal that a bad news is coming, but the approach seems milder.

> ...even from the mood *'you came with somebody', I knew my result was positive (ht0484fn).*

**Additional sorrow/ Crying, crying, crying:** Though the HIV-positive IV drug users are diagnosed earlier than other groups (Kivelä 2009), they still suffer the pain of being pronounced positive. So for a Finnish participant whose life was already being devastated by drugs, testing positive to HIV made her unhappy life even worse.

> *...is like my life wasn't happy before it, now it was like even more unhappy (sn9975ff).*

For her Nigerian counterpart, who tested positive to the disease during antenatal check-up, ceaseless crying became her companion – especially when she is

alone. She said it was mainly because there was not much awareness on the disease as it is today. However, her sorrow reduced greatly after coming in contact with 'doctors without border' who restored her hope.

*And then I was pregnant, and when I am alone if you see me I will be crying, crying, crying. Crying I will think of the baby, think of me whether am going to be alive because the awareness wasn't like this then. Then when I got in contact with doctors from borders (i.e. doctors without borders), those white people, they gave me hope, when my hope was lost (aw0071fn).*

For another Nigerian participant who tested positive to HIV shortly before her graduation, she moved on with her life after crying for a whole day.

*When I got to school I couldn't tell anyone. I cried for the whole day, and I moved on with my life (as0481fn).*

While many men see crying as something associated with kids and women, and some women claim too bold to cry because it is a sign of weakness, in reality, crying is medicinal. A person who feels secure enough to cry and release inner emotions can be quickest to recover from the circumstance that led to it because shedding tears gives a person the opportunity to begin to heal and recover from a loss, disappointment, grief, and so forth (Orr 2003). These two similar themes show that while the Finnish participant sees HIV-positive result as an additional sorrow, her Nigerian counterparts felt secured enough to cry which perhaps aided them in recovering from the shock of being pronounced HIV-positive.

**This is it/ The end:** The London live musical concert which Michael Jackson did not live to perform was titled – 'This is it'! This connoted that the show was going to be the last of such performance. Using the same expression, a Finnish participant tried to illustrate how she felt after testing positive to HIV. That is – her life had come to a full stop, but over the year as she became better informed, the devastating thoughts disappeared.

*...basically when I found out I thought that this is it, am dying good bye, but over the years I just realised that is not like that life goes on you know ... I think I thought that am dying and soon, I have no idea what was happening because I didn`t have so much information about the drugs and everything, I was thinking that okay this is it, I have few years or something, so yeah it was really devastating but after when I had time to think about it and people like nurses explain everything about it and so yeah, the first reaction was death or something similar (sh0485ff).*

Such thought is in accordance with Clarke (2004, 232) which states that "the first reaction to testing positive was the fear of death and the fear of stigmatization". Furthermore, two of the Nigerian participants had similar experience.

*I thought that was the end, I thought that was the end (as0481fn).*

*As a human being, is normal to think, the image that comes is death, that first impression was created (aw0071fn).*

**Being hurt/ Being ill treated:** To one Finnish participant, testing positive to HIV is being hurt. Pin-pointing what did hurt her she said it is the disease itself,

and not her knowing that she is HIV-positive. To her, the best alternative is not to have the disease, however, since knowledge is power (Vickers 1992) the next best alternative is to know that one has it, while the worst alternative is to have the disease without knowing it. Comparing the disease with cancer, she prefers to know that she has it, so that she can begin taking care of herself on time.

*I think I have been hurt by the disease, and not by knowing it, I think the best alternative will be not to have it. The next best is having it and knowing that you have it, and the worst will be to have it and not know it. Is like if I will get cancer, I will like to know that I have cancer, even if I will know that am gonna die of it, I would like to know. (So that you start taking care of yourself?) yes, yes (sn9975ff).*

Another Finnish participant who thinks the same way says though knowing increases responsibility and pain, she still prefers to know and be cautious in order not to infect others.

*Knowledge increases the responsability and pain, but I'd rather know it than to infect enyone else (ms9367ff).*

Then for a Nigerian participant, she is hurt by realising that her ex-boyfriend deliberately infected her with the disease, and she sees it as 'ill treatment and cheating'. She believes that the ex-boyfriend should have given her the chance to choose whether to live with him that way or not.

> *His own response to the whole thing was what made me panic a bit. Well, along the line it was obvious that he knew he had it but couldn't face me to tell me, I felt ill treated, because to me I believe he knew his status and didn't tell me. So he would have allowed me make the choice – if I want to live with him that way or not. So I felt a kind of ill treated and a bit cheated too (tp0389fn).*

In Finland and many other western countries, attempts such as having unprotected sex with the knowledge of one`s HIV-positive status may even attract a prison sentence, however, in Nigeria where many civic laws are not implemented, individuals walk away with such crimes.

**No big deal/ Unscarred:** Although the news of a positive result is not a good news to anyone, but for one Finnish participant it was also not a big deal because she thought she was going to die of drugs addiction anyway, so testing HIV-positive did not make much sense to her.

*It really didn`t, it wasn`t that a big deal you know when I heard it, it wasn`t like good news, well I thought I will die of the drugs before I die of the disease (sn9975ff).*

But for a different reason her Nigerian counterpart was not scarred or moved by the positive result news. The reason was that she had already acquired some knowledge about HIV/AIDS and knew that it is not a death sentence. However, something else as seen in the above theme was what greatly scarred her, which is being infected deliberately by her ex-boyfriend.

> *It couldn't move me, and I said really? Okay. I was not scared at all ...so I just graced up.... Hearing the news I wasn't scared because I have little knowledge about what HIV/AIDS is all about, and I knew it wasn't a death sentence, I knew from the awareness, from the little knowledge that I have*

*gathered I knew it wasn't a death sentence. If you test positive to HIV disease, the next thing that come to your mind is for some, for some it could be really a death sentence actually (tp0389fn).*

**Undisclosable big dark cloud:** There have been many studies on how human mind works; nevertheless there are still vacuums in the explanation on why some things happen in the mind. One of which is that for a period of about six months after testing positive to HIV, a Finnish participant said she carried about a kind of big dark cloud in her mind which she was unable to disclose, and the hopelessness that embodied the dark cloud contributed to messing-up her life.

*And then it was this, it was a long time, maybe 6 months it was just this big, big dark cloud inside my head, I didn't want to talk about it, I didn't want to tell anyone, I just walked around. My life was just a mess, I had no hope at all (sn9975ff).*

Another Finnish participant who experienced similar bitterness suffered it only for a short while after she tested positive, and her life went back to normal.

*Like when I found out that period really rocky and stuff, but after that I think life went back to normal basically (sh0485ff).*

**Self-pity and drinking:** Self-pity is a common response after a stressful incident. Stober (2003) reveals that it has strong associations with neuroticism – particularly depression. As such, learning that one is HIV-positive may open doors for drugs use, destabilisation of relationships, income and shelter loss, and so forth (Stevens and Doerr 1993). So discovering that she is HIV-positive, self-pity became the companion of one of the Finnish participant, and that was accompanied with heavy alcohol consumption during her search for relief. Nevertheless, that unhealthy lifestyle lasted only for a while. Her attitude has since changed, and now she hardly thinks about the disease especially because she is aware that worrying cannot reverse her status.

*When I found out, that was a short period of self pity and drinking, but after that I haven`t really thought about it because at least in my mind you know sickness have happened what`s the point of like going over them because what happened happened, it could have happened to me or someone else (sh0485ff).*

**Limited social life:** HIV/AIDS often affects the quality of life of the PLWHA (Skevington, Norweg and Standage 2010). In this regard, one Finnish participant acknowledged that her social life has been affected by the disease. This was manifested in her being limited in many ways by the initial shock of being pronounced HIV-positive.

*My social life was limited quite a lot in the beginning. Mainly because of the initial shock I had (ms9367ff).*

**Recovering from lousiness:** For one of the Finnish participant testing positive to HIV served as a wake-up call which aided her recovering from lousiness. While this participant was studying in another EU country, she escorted a friend

to a sexual health clinic for a HIV screening, and reluctantly chose to be screened too. Though she did not say what her friend`s result was, but unfortunately she tested positive. At this time in her life history a number of things might have happened, but among the most notable ones are lousiness, inabilities to take academic pursuit serious, and loss of her sense of purpose. However, testing positive to HIV served as the much needed wake-up call which added a new perspective to her life.

*I think that before I knew I got it, I think I was lousy at (Name of the place withheld), try to study a bit and didn`t know what to do with my life and emm you know, and then when I found out is like. In the beginning I really thought that am going to die soon, younger, or something, like it really pushed me to achieve my goals like to study and start thinking what I will want to do. Obviously someone die at some point but when you get some reminder that you are going to die at some point, then it can like put new perspective, I wanted to do like something with my life, I wanted to do sooner than wonder around (sh0485ff).*

### 4.2.4 Summary of conceptions on testing positive

In this sub-category, a total of 14 themes (9 and 5 from the Finnish and the Nigerian participants respectively) emerged on the meanings of testing positive to HIV. Five of the Finnish themes are similarly different with the five themes from the Nigerian group, while the other four from the Finnish participants differ completely. Starting with the related different experiences; while a Finnish participant is displeased how she was informed about her positive result; her Nigerian counterpart believes that hers was polite enough. Again while testing positive means to a Finnish participant 'additional sorrow', it mean to two of her Nigerian counterparts 'continuous crying', and to the Nigerian participants that might have served as additional healing balm. Another shared experience is on the thought of dying soon, but fortunately the participants from both group said their fears disappeared after they became better informed about the disease. The fourth area is in their being hurt; while a Finnish participant believes that is being hurt by the disease itself and not by knowing it, her Nigerian counterpart believes that she is hurt by her ex-boyfriend whom she believes deliberately infected her. Then the fifth shared experience is in their not being moved by the HIV-positive results. A Finnish participant was not moved because she believed her drug addiction was a worse nightmare, but her Nigerian counterpart was not scarred because she had acquired a prior knowledge that HIV/AIDS is not a death sentence as it is often projected.

The other four different responses from the Finnish participants on testing HIV-positive are: a big dark cloud inside the head, self-pity which led to excessive drinking, seeing the disease as a wake-up call needed for recovering from lousiness, and then the view of the disease as an agent for limiting social life.

For further insight, concept maps in figures 13 and 14 in pages 101 and 102 separately mapped out the overall emotional/ mental health impacts of HIV on the Finnish and Nigerian participants, and table 13 in appendix II shows the comparison between the Finnish and Nigerian participants` experiences with

testing positive to HIV, and the comparison was also backed with findings from earlier studies. The next sub-category is titled 'Acceptance', and it explodes the participants` experiences with accepting the disease and the new identity that comes with it.

### 4.2.5 HIV acceptance

Accepting HIV/AIDS positive status is difficult especially because it means accepting a new and undesirable identity. The unattractiveness of this identity is often because the predominant plots of the disease are: gay, immorality, promiscuous sex, prostitution, drug use, and so forth (Clarke 2004), and such identities are not generally accepted in many societies. The acceptance is even made harder by the fact that is not all the PLWHA who are associated with the attributes for which the disease is identified with. So as a means of avoiding discrimination, self stigmatisation, and depression, many of the PLWHA have either refused to accept the disease, or do not see it as part of their everyday life. This sub-category analysed the responses of participants in respect to admitting their positive status. The themes under which the Finnish participants` attitudes were analysed are: confirmation test, hard to accept, identity crisis, and permanent stamp. While that of the Nigerian participants were analysed under: no choice, hard to accept, not running to churches, and living fine.

**Confirmation test / No choice:** After a HIV/AIDS positive result, a confirmation test is often done to affirm the result. The goal is to avoid giving individuals false-positive results. As such, two Finnish participants said another test was conducted on them to confirm the first quick one.

> *There was another test done, after the first 'quick' one. It was a long time ago, I don´t remember any details (sn9975ff).*
> *The doctor gave me an open note telling me to take it to the lab. I had to be tested for second time (ms9367ff).*

Then a Nigerian participant expatiating on the need to accept a positive result admonishes that, others should imitate her who after a confirmation test accepted her fate because she has no choice.

> *...when you go for that test and they say you have the virus some will say God forbid. It was very easy for me; I accepted it because there is nothing I can do about it.... It was when I went for confirmation; I thought they will give me another report. But that day I waited after the result came the same, I accepted my fate.... Yes, there is something like that (false-positive) because some of the machine they are using outside, some of them doesn't give you the correct result. That is why if you do it outside lab, they will send it for this thing, for confirmation (aw0071fn).*

So while it is necessary to accept one`s positive result, confirmation test is necessary to backup the first positive test result, or to refute it; and it is necessary not to delay it in order to minimise or reverse the psychological effects of a result which is only but false-positive. For instance, I know about a Nigerian

lady who`s first screening showed positive and the later negative (false-positive). But prior to the second screening few weeks later, she had already suffered much emotional stress. So, while the confirmation screening is important, to avoid unnecessary stress, the second screening should not be delayed.

**Hard to accept:** Accepting the HIV/AIDS identity for many causes a lot of intrapersonal struggle. In Anderson and Spencer (2002, 1347-8) one participant in demonstrating such struggling said, *"I hate that word. I'm still trying to accept it, I think. Yes, I am trying to accept it"*. In similar manner, accepting her HIV-positive status for a Finnish participant is a continuous mental struggle, and till date she has not completely accepted the disease as part of her identity nor has the plan to do so.

> *...mentally it was hard to accept. I have yet not accepted this disease, nor I ever will. It is not part of my identity (ms9367ff).*

Then recounting from her experience, a Nigeria participant said it was really hard for her to accept, however, she is encouraging those who tested positive like herself to embrace their fate instead of hiding or asking questions which lead to nowhere.

> *...for me it was really hard... some people might get infected and still hide themselves. Haa! It can`t be me, how did I get it? Why should you be questioning? (ht0484fn).*

**Identity crisis:** The disease is often linked to different kinds of social vices that sound shameful and unacceptable, and because some of the PLWHA will not want to accept such identities too, they frequently suffer identity crisis. A foretaste of such identity crisis was captured in the response of a Finnish participant.

> *...is not part of my identity although is in me, is not who I am ...probably it has affected my my self image different times in different ways (sn9975ff).*

**Permanent stamp:** Again a participant in Anderson and Spencer (2002, 1347-8) said, *"It's finally sinking in that I do have it and I'm starting to feel lousy about it"*. Similarly, a Finnish participant sees the disease as a permanent stamp in her life.

> *I guess is a part of me, nowadays is something I will have to live with the rest of my life (sn9975ff)".*

Another Finnish participant who agrees with her says:

> *We are to change what we can and to accept what we cannot change and to ask wisdom to know the difference between these two (ms9367ff).*

**Not running to churches:** In Nigeria where religious sentiments are increasingly becoming attached to almost everything (especially the Christian religious), beliefs are often abused by those who go to the extreme. As such it may not be surprising that some Nigerians, who are not naturally religious in reject-

ing positive test result of undesired diseases like cancer and HIV/AIDS run to churches in search for miracles that will reverse their positive test results. Nevertheless, a Nigerian participant did not follow such footstep; instead she accepted the disease in good faith which has made her whom she is today.

*Well it`s one thing to know your status early, and another thing to accept it. When I got to know my status I didn't fight it like it`s not my portion. I didn't run to churches, I didn't run to you know like our mentality here – trying to seek help where there is none, I accepted it in good spirit and moved on. That as a matter of fact brought me to where I am today. So is one thing to know your status and another thing to accept it... accepting it is another thing, another big challenge (tp0389fn).*

**Living fine:** Similar to Fryback and Reinert (1999) which reveal that cancer and HIV/AIDS patients who are positive about their disease experience better quality of life than before they were diagnosed with the diseases, a Nigerian participant who has accepted the disease in good faith said she is happily living with it.

*Normally you will think about that, 'how I wish I don't have it', but will you blame God for everything? When I had it I felt so bad, but right now am happy, and am living fine (as0481fn).*

### 4.2.6 Summary of conceptions on HIV acceptance

A total of 8 themes emerged in this sub-category, (4 apiece). The participants hope for negative results were dashed after their confirmation tests proved that they are truly HIV-positive. The two groups find accepting the disease very tough, however their accepting it has been rewarding. Then while the Finnish participants see the disease as an agent for identity crisis and emblem of permanent undesirable stamp, their Nigerian counterparts believe that the disease should better be accepted in good faith which is the only way for PLWHA to happily live with the disease.

For further insight, concept maps in figures 13 and 14 in pages 101 and 102 separately mapped out the overall emotional/ mental health impacts of HIV on the Finnish and Nigerian participants, and table 14 in appendix II shows the comparison between the Finnish and Nigerian participants` experiences with accepting the disease, and the comparison was backed with findings from earlier studies. The next sub-category examined the emotional stress the participants of this study are experiencing due to their HIV-positive status.

### 4.2.7 HIV related emotional stress

Stress is increasingly becoming a major global health problem, but what many fail to understand is that the stress that harms most is not the physical stress but the emotional one. This sub-category explores the emotional stresses that are associated with living with HIV. From the Finnish participants, the themes under which emotional stresses were described are: 'feelings of hiding from people, short time of being weary, loneliness and sadness, drinking heavily, suicide

thoughts and attempts, guilt, prison of shame, and sometimes a big issue'. While those of the Nigerian participants are limited to: 'painful separation and hardship due to less productivity'.

**Feelings of hiding from people:** While one Finnish participant said living with HIV has created the feeling that she should be hiding from people.

> *I think is the barrier I create myself you know inside, you know I have this feeling that I have to hide from people (sn9975ff).*

Another who nurses similar feeling said living with the disease makes her feel old and unattractive notwithstanding that people tell her otherwise.

> *I feel unattractive and old, even though people thell me otherwise (ms9367ff).*

Perhaps it takes being a lady to catch a glimpse of what emotional stress the above Finnish participants are passing through. For instance, in the present generation where pretty appearance and public display of beauty and clothing matter so much to ladies, for one to be secluded is a disease of its own. Similar feelings were found in NordPol (2007) where the respondents sense that sometimes people are afraid of them, and as such keep physical distance from them.

**Short time of being weary:** Two of the Finnish participants claimed that living with HIV have not really made them depressed but something similar. One claimed that instead of depression what she feels is short times of weariness.

> *I can`t say that I`ve had depression as the disease depression you know but just this short time of being weary. I have never really been depressed about it (sn9975ff).*

Another claimed that living with HIV does not make her depressed, angry, bitter, or worried, instead all she nurses is the feeling that the disease is in her.

> *Am not angry, bitter, it just am living with it, I don`t get depressed or thinking about it (sh0485ff).*

This may mean that no matter how hard some try, the feelings that one`s life has been forever changed keeps reoccurring. But like one participant in Anderson and Spencer (2002, 1345) who does not want to over stress himself said, *"I try not to let it bother me because my viral load and everything is real low"*, PLWHA need to find reasons to be cheerful always in order to avoid the problems with fixing the mind on the disease. After all, cheerfulness is a good medicine[30].

**Loneliness and sadness:** No matter how hard some individuals may try to act otherwise, humans are social beings and doing the opposite is not only tough but harmful to health. Living with HIV can even worsen one`s situation by in-

[30] Proverbs 17:22

creasing the atmosphere for feeling lonely even in the midst of people. In Nigeria where individuals are used to being surrounded by others (sometimes against one`s wish), HIV related isolation could could affect an individual differently from individuals in Finland where many are used to staying alone. As confessed by a Finnish participant, she often feels lonely but fortunately such feelings have reduced. However, her greatest concern is that her daughter who is her closest companion will soon move away from her because she will soon turn eighteen, as such this participant believes that her future will most likely be a lonely one.

*I often feel lonely and sad, lately not as much as before. My daughter is soon flying away from the nest as she is becoming of age. I wonder how it is going to be, when my daughter moves out. I see my future rather lonely. (ms9367ff)*

For migrants the situation could be worse, according to Clarke (2002), coping with loneliness is the biggest challenge for immigrants in Finland who are living with HIV/AIDS.

**Drinking heavily:** Learning that one is HIV-positive may open doors for illicit drugs use, destabilisation of relationships, income and shelter loss, and so forth (Stevens and Doerr 1993). But what many do not often realise is that alcohol addiction like every other addiction (either to a substance or non-substance) does more harm than good (Hamajima et al. 2002, BBC April 2004, Morgan, Mandayam, and Jamal 2004, Key et al. 2006, BBC August 2009, Nutt, King and Phillips 2010, Yle October 2013a, Yle November 2013a). But unfortunately, once some individuals come across undesirable experience, alcohol becomes their closest companion. A Finnish participant who became depressed after testing positive to HIV said, she soon after began to binge alcohol for about six months, but luckily she recovered from it.

*Yeah! I was really like depressed, and I think that I was really like drinking heavily.... I think it was something like 6 months I was really like out of it, but then I just process it (sh0485ff).*

But unlike in Finland and other western countries, in Nigeria due to the inability of many to afford it, couple with pressures to uphold family`s honour and religious values, alcohol consumption is relatively low. Furthermore, unlike in the western world many of those who binge alcohol are tagged wayward[31].

Then apart from the fact that alcohol serves as a gateway substance for addiction to other drugs, many studies have shown that it is related to cirrhosis of the liver, peptic ulcer disease, increased cancer risk, increased infectious diseases, high blood pressure, stroke, impaired sexual function, osteoporosis, gout, heart problems, low blood sugar, chronic fatigue syndrome, and so forth (Boonstra and Finley 2006). But because human body can withstand or suppress alcohol

[31] Although some ladies in Nigeria drink alcohol and smoke cigarette, it is nevertheless generally believed that they do not.

immediate effects, young people increasingly binge it without caring about what harm they are doing to their bodies (Hardinge 2007).

**Suicide thoughts and attempts:** Stevens and Doerr (1993), Clarke (2004), and Préau et al. (2008), reveal that the first set of reactions to testing positive to HIV are shock, fear, anguish, and suicidal thoughts. In Anderson and Spenser (2002, 1348), one participant who wanted to take his own life said: *"When I first found out, I wanted to kill myself and just get it over with. But now it's different. I want to live and just live out the rest of my life"*. Similarly, the three Finnish participants in this study had at one point or another thought of committing suicide, one even made a failed attempt.

*I think maybe at some point, it was the time I was living in [name of the place withheld], I had just moved there and found out that I had no… (sh0485ff).*

*Well when I was using [drugs], not after I quitted (sn9975ff).*

*I tried it several times. Did not succeed. It was mostly because of the depression (ms9367ff).*

Perhaps the suicide thoughts and attempts exclusively came from the Finnish participants because Finland has one of the highest suicide rates in the world (Yle July 2012).

**Guilt:** Amongst PLWHA guilt and anxiety may a common phenomenon (Clarke 2004). Two of the Finnish participants said they do nurse such feelings. To one the feelings come once in a while (that is the feelings that she brought the calamity upon herself by not taking necessary precautions despite the fact that she knew its important), however, such feelings no longer occur as frequent as it use to.

*Sometimes. I did this myself by not protecting myself. By allowing myself to get into a situation like that even though I knew better. But not so much anymoree (ms9367ff).*

The other seeing it as her fault said she knew what to do protection-wise but did not do so.

*I knew what to do to protect myself but I kind of didn`t do it, it`s kind of own fault (sh0485ff).*

**Prison of shame:** Using a thought provoking and artistic language, a Finnish participant made an attempt to express some of her deep emotional stress. Having been forced by the disease to somehow isolate herself from the society, she believes such living condition is tough, and the imaginary walls tougher, however if the imaginary walls are to be broken, there will remain the prison of shame inside.

*It is hard to be a social recluse. Even harder to understand that the imaginary walls are the thickest and that even if they were to be broken, the prison of shame is inside you (ms9367ff).*

In theatre art, an imaginary wall [also known as the fourth wall] was first described by Denis Diderot, and it became popular in the 19th century theatre. As a metaphor, breaking the fourth wall connotes looking beyond the ideal three walls of a performance setting to see the audience or other individuals (McKellen 2013). So to this participant who believes that the disease has isolated her from the society, there seems to be the feeling that even if she is to be fully reunited to the society, there may still remain prison of shame inside her; and her case may not be an isolated one. So for PLWHA who nurse such imagination, there are great needs for psychosocial supports, and providing them remain the primary duty of HIV/AIDS organisations (Clarke 2004).

**Sometimes a big issue:** Without painting unrealistic rosy pictures, a Finnish participant confessed that the emotional stress of being HIV-positive fluctuates in her; while in some days it is a big issue, in others it is not.

*So I can`t say is not a big issue in my life. There are days is not an issue, but there are days and night is a big issue, it goes up and down (sn9975ff).*

**Painful separation:** Knowing that one is HIV-positive may open doors for relationship destabilisation (Stevens and Doerr 1993). As such, for testing HIV-positive, one of the Nigerian participants experienced painful separation for which she was unexpectedly pushed out of her matrimonial home while her baby was barely two weeks old.

*My first husband sent me packing while my baby was 2 weeks old, so I catered for the child and move on with my life (as0481fn).*

Another Nigerian participant said, the death or sudden disappearance of husbands to some HIV-positive women forced them into playing the roles of both parents.

*I think women who are positive you know, some their husband ran away, some their husband is late you know, so they are left with the burden of taking care of the children (tp0389fn).*

**Hardship due to less productivity:** Living with HIV/AIDS in one way or another reduces productivity, which also reduce income, and one`s ability to meet up with essential financial responsibilities. As such, one of the Nigerian participants is often emotionally stressed by the hardship she faces due to reduced productivity and income, and the situation gets even worse at each time she falls sick.

*Is when things are tough, when am getting sick, and when financially everything is [tough] I will start thinking, which is because one can no longer do the active and productive like before (aw0071fn).*

Of course, this Nigerian participant`s anguish is shared by many PLWHA, in Anderson and Spencer (2002, 1345) one participant expressed it thus: *"It just took my whole life and turned it upside down. I can't do a lot of the things I used to. I lost a house because of it. Everything I worked for I lost".*

### 4.2.8 Summary of HIV related emotional stress

A total number of 10 themes (8 and 2 from the Finnish and Nigerian participants respectively; see figure 12) emerged in this sub-category. There is almost no similarity amongst the themes; however, they all reveal that there are handfuls of emotional stresses associated with living with the disease. One of the most obvious things in this sub-category is that based on the responses from both group, it seems the Nigerians participants have experienced less emotional stresses probably because they are more positive about their condition than their Finnish counterparts. This outcome seconds a surprising outcome in the first category (Knowledge and Understandings on HIV/AIDS), where the Finnish participants expressed more negative sides than positive ones, while their Nigerian counterparts did the opposite. Perhaps this outcome is also because the Finnish participants are more vocal about their emotional stresses than their Nigerian counterparts.

For further insight, concept maps in figures 13 and 14 in pages 101 and 102 separately mapped out the overall emotional/ mental health impacts of HIV on the Finnish and Nigerian participants, and table 15 in appendix II shows the comparison between the Finnish and Nigerian participants` experiences with HIV associated emotional stresses, and the comparison was backed with findings from earlier studies. The next sub-category examined the participants coping strategies.

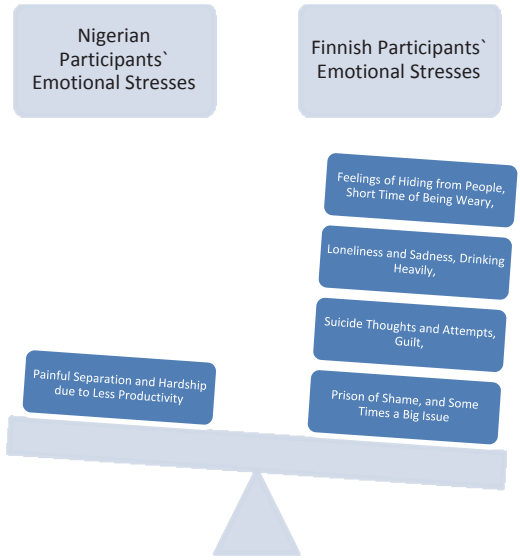


**Figure 12.** A Comparison of the emotional stresses of the participants

### 4.2.9 Coping strategies

This is the last sub-category discussed under mental/ emotional health impacts of HIV/AIDS. Here the various strategies the Finnish and Nigerian participants have employed in coping with the disease are explored. The ones employed by

the Finnish participants are described under the following themes: ‘not part of everyday life, less thinking, love to live, fight back, someone to talk to, and meeting and supporting one another. While the Nigerians` are: just someone with normal illness, not thinking, love to live, self esteem, self support, visiting one another, support group meetings, being strong, no to sorrow and self-pity, helping others, public support, true empowerment, and standby HIV-positive counsellors. All the themes are based on the participants` stories of how they have been managing the disease. Most of the strategies have come directly from their immediate experiences; and the other few from their perceptual thoughts.

**Not part of everyday life/ Just someone with normal illness:** Thinking about HIV/AIDS can be very problematic in the sense that it makes PLWHA to feel that the disease is much an obstacle in their life than it really is. As an antidote against such feelings, a Finnish participant has refused to make the disease a part of her everyday life.

> *The disease is not part of my everyday life, I don`t really think about it ...but in general I think it has it has like inside my head (sh0485ff).*

The later part of the above response shows that the participant lacks words to completely express what goes on in her mind, nevertheless, just like in Aga, Kylmä and Nikkonen (2009), where the imagery of chronic disease was used to minimise the weight of AIDS, a Nigerian participant similarly said that she identify herself as someone with normal illness, and not as someone with AIDS which though often used together or interchangeably with HIV is the more dreadful part of the disease. Like her Finnish counterpart, the Nigerian participant has not made the disease a part of her everyday life, but instead thinks about it only when she is sick.

> *I don’t identify myself as someone who has AIDS, I identify myself as just like someone with normal illness, I don’t have it in my mind [always]. I think about it when am down (aw0071fn).*

For another Nigerian participant, though she is aware that the disease is in her, she does not believe that she has it, as such, she lives as though nothing is wrong with her.

> *I never even believe that I have HIV, I live like a normal human being, nothing is wrong. I know I have it but I never look like someone who have it, so it never have any effect on me (as0481fn).*

Of course knowing that one has a particular illness and not believing it sounds like a paradox, however, the most important thing is that such state of mind has been helping her to cope with the disease.

**Less thinking/ Not thinking:** As a follow-up to the first coping strategy, a Finnish participant said she does not always think about the disease because it is difficult to be scared, especially for something one does not know.

> *I don`t think about it often because it`s really difficult to be scared about something you don`t know (sh0485ff).*

But since she is not completely a stranger to what the disease is about, it seems she mean being scared of what tomorrow will bring to her due to the presence of the disease in her. Then taking a step further, a Nigerian participant said she does not think at all; not even of the disease. She admonishes others to be cheerful always which though simple seems almost impossible in a world full of worries. She also admonishes that; individuals should share things bordering them.

*I don't think about it, I don't even think. They should try to be happy always. They shouldn't think about anything, they shouldn't let anything border them.... If they have anything in mind that is bordering them let them share it so that there will be a solution (as0481fn).*

Another Nigerian participant believes that, while not thinking about the disease may not be achieved in a day, prayer also helps.

*Initially when I feel sad I think about it, and then I just pray this thing may not kill me, this thing may not kill me, but now I don't, for once I don't even think about it. I don't let it border me.... The first thing is to remove their mind from the virus (ht0484fn).*

**Love to live:** Humans generally love life over dying, but it is not always so. Yle (July 2012) reported that, with around 30 girls taking their own life every year, Finland has one of the highest suicide rates in the world, and it is often as a result of stress over appearance, money, addiction and marginalisation. Nevertheless, for many of the PLWHA reverse is the case. For instance, after being devastated by the news that she tested positive to HIV, a Finnish participant whose life was wasting away got revived, and the turnaround was solely because her choosing to live rather than dying.

*I think that I had some ideas like what to do now, like is worth living and stuffs, but then basically at some point, I just decided that okay, do I really want to die or do I want to start on living, I just decided that okay now it is time to get up from the bed you know push it so (sh0485ff).*

Two of the Nigerian participants also said that, at a point they chose life rather than death.

*...just for me I have taken the decision am going to live, am not going to die.... Even something I still do now; I wake up some time and look at myself in the mirror and I say, I speak for myself I`ll regain HIV you are not going to kill me! You know just like that, that is one way am encouraging myself, so fighting is you encouraging yourself, accepting it in good faith, and moving on with your life (tp0389fn).*

*...immediately is 8 o`clock the alarm will remind you. Although is not easy, is not a very easy thing but the decision again depend on me, i.e. I have that decision to live.... Some they will still ask them, some fail to adhere to the instruction, for me I really want to live, I really want to take care of the children God has blessed me with, I really want to live for that man who has been standing by me (aw0071fn).*

**Self esteem:** Low self esteem is a problem for some individuals, and due to the exceptionality of HIV/AIDS, PLWHA are much more prone to it. Nevertheless, a Finnish participant said she has gradually regained her lost self-confidence.

*You know life, I didn`t have any goal in life you know the future didn`t seem like anything great to look forward to it, but now and so the disease is just one thing you know, but when I got clean and started living a normal life and step by step I have built myself consciousness, I have started to consider myself as a normal human being (sn9975ff).*

Her Nigerian counterpart who believes that self empowerment is a way forward said:

*...they should empower themselves in many things; they can do business, they can go to school... so they should empower themselves. They shouldn't look down on their selves, they should look their selves as a normal person. When they look their selve am okay, they will move on with their life. But when they look their selve ah very soon I will die oh, they will fold their hand, they will not be able to do anything, they will be powerless (as0481fn).*

**Fight back/Self support:** Holzemer, Henry and Reilly (1998) study of 249 AIDS patients associated higher level of pain to lower quality of life. So, to improve the PLWHA`s quality of life a Finnish participant suggests that putting up strong fight-back against the disease is essential especially for the benefit of younger PLWHA.

*We must fight so that the ones who come after us would have it easier! ...I was told by a younger positive woman how she always admired me and thai I was kind of an example for her. She too started to study.... All in all, I feel like I should never ever give up (ms9367ff).*

Another Finnish participant said that her own way of fighting back is by living in a way that the disease will in no wise hinder her from doing thing.

*I want to try to live so that it doesn't keep me from doing things, I want to like achieve things, maybe that, I want to work against my feelings that say hey don't do this... I have had this disease for a long time, I have had all these years to you know think about it and come to peace with it (sn9975ff).*

Three out of the four Nigerian participants also see the need to improve quality of life through living healthfully and positively. One of them who listed five positive steps said PLWHA should always use condoms, eat a lot of fruits, rest well, remain always cheerful, exercise physically, and drink a lot of water.

*First of all, they should not have sex without condom, they should try to protect their selves always except they want to have baby. Secondly, they should eat fruits a lot. Thirdly, they should rest, they should find time to rest, and they should make sure they are happy always, they don't feel sad. Someone who is living with HIV can exercise – nothing is wrong with that. Make sure they drink a lot of water (as0481fn).*

Another suggests that PLWHA should eat good food, take good care of themselves, and also treat illness as they come. Using herself as an example she said she has a good image of herself and adheres to her doctor`s prescriptions.

*You take good food, take good care of yourself, if you have any illness treat it. I have good image about myself, I don't allow the disease to put me down. All that I knew was that I kept to the instructions of the doctor…. When you live your life positively, you will live as long as God want you to live (aw0071fn).*

The third laid emphasis on claiming and living positively with HIV.

*I noticed the doctor that counselled me, even the counsellor herself made mention of how intake of minerals and vitamin can help…. So anyone who is going to come out to disclose his or her status now will say "am a positive living positively with HIV", so is just about positive living for those who are already HIV infected (tp0389fn).*

**Someone to talk to/ Visiting one another:** Humans by nature are social beings, and as such socialising may be medicinal. So while anxiety and depression remain the most common psychological problems for PLWHA (Virk 2011), through talking to people one can better manage them. A Finnish participant sees taking this measure as an antidote against sorrow and loneliness which equally aggravate anxiety and depression.

*Someone to talk to... when I feel lonely or feel sad, it make me feel even more lonely or sad... but I have people I can call, people I can yes HIV-positive friends, and also other friends, calling them helps me to recover from lonely feelings (sn9975ff).*

Another Finnish participant who already has many friends to talk to acknowledges that it is not all the PLWHA who are privileged as her.

*I have so many friends, I always talk with them, ...but I know there are so many people who are lonely and don`t have so many friends, so it will be really good for them to have a kind of like long-time relationship with someone to talk to, is really important (sh0485ff).*

Furthermore, in line with Issiaka et al. (2001) study of the experiences of HIV-positive women in Burkina Faso, which show that one out of every two women wished to meet another infected person in local NGOs to share with, a Nigerian participant said that a group of PLWHA visiting their fellow as her unit does, helps in fighting the stigma and discriminations faced by many PLWHA in their neighbourhoods.

*Is actually like when we pay a visit to their home, when they see the rest of us, they know that is not just one person (tp0389fn).*

**Support group meetings:** Peer-support meeting is becoming increasingly important (Harris and Larsen 2007). Among other benefits, it promotes adherence to HIV/AIDS medications (Marino, Simoni and Silverstein 2007). Throwing her

weight behind such meetings, a Finnish participant who belongs to a HIV-positive ladies group said:

> *Positive people meeting each other and supporting you know like – hey we can do it you know a group is always stronger than one person, I know that I have gotten a lot of support from people that had it longer than me, And also it has helped me, and I know I have helped other people who have now just found out about their disease. I can tell them hey I have lived with it for 12 years you know; it hasn't really affected my life that much... it is very supportive, and they are helping me to cope with it…. Just you know support, knowledge and information, and phone numbers and contacts... if I have something I really need support about it, yeah I got sometime this positive ladies – positive women group (sn9975ff).*

Another Finnish participant whose group sometimes go to watch movies suggests that in Finland support group meetings should be more frequent than it is presently.

> *In Finland, I think that it will be really important for HIV people, like positive people to see each other more ...in Finland the circles are so small, so l think it`s real difficult for people to reach out and get to know other people with HIV, so then they could see that they are not alone ...we go out, we go sometimes to movies, you know something have fun together (sh0485ff).*

A Nigerian participant describes support group meetings as the best forum for PLWHA to share all manners of challenges which cannot be shared elsewhere.

> *Support group is a place where you can come and share experience with PLWH, we come there to share our mind. If you have problem, if you cannot tell another person at least you have your brothers and sisters, [and say] this is what is bordering me oh, if any of us has solution to the problem, we will tell that person (aw0071fn).*

Another additionally describes the group meetings as their opportunity to share experiences and challenges.

> *The support group we meet share our different experiences and challenges; whatever it is one has suffered. Some it could be financial problems and especially when the love and support is not there (tp0389fn).*

**Being strong:** For every challenge, there is a cross, and living with HIV is not an exception. As such, a Nigerian participant sees being strong is an effective tool for coping with the social challenges imposed by living with HIV. She said employing the tool plus relying on God had been very helpful.

> *I never felt bad, I never felt bad because I know I will come across it (discrimination). It never affect me because you don't need to talk to anybody except God (as0481fn).*

The experience of this participant is in congruence with Farber, Schwartz, Schapner, Moonen and McDaniel (2000) study where it was acknowledged that

lower psychological trauma in addition with better quality of life plus self-esteem enhances coping with HIV/AIDS.

**No to sorrow and self-pity:** Condemning social anxiety disorder, a Nigerian participant said that, it is not good to feel sad because it`s tantamount to killing one`s self which PLWHA should avoid at all cost.

*Is not good to feel sad, if you feel sad you are killing yourself. If you have anything in mind you are killing yourself – that is what HIV did not want! I know what HIV want and I know what it does not want, so if I do it I will be killing myself (as0481fn).*

Another Nigerian participant is not that sorrowful about her condition because she has been forewarned by her doctor that depression kills faster that any condition that leads to it. In addition, her dad who received the same education has pleaded with her to at all cost avoid being depressed.

*One the doctor told me that depression is one thing that kills faster. Not just with someone living with HIV, but depression in any illness kill faster than the illness itself. So my dad pleaded with me not for any reason get depressed (tp0389fn).*

A third participant among the Nigerian group from her experience said that feeling sad means bringing problem upon one`s self. She had framed her mind in a way that living with the disease does not make her feel sad anymore.

*As a person, when I start feeling sad, I will start bringing problem to myself. It doesn't make me sad, am always happy (aw0071fn).*

**Helping others:** It may sound strange that helping others in need serves as a coping strategy for PLWHA, nevertheless, it seems logical. It is more of a psychosocial cure of which while an individual engages his/ her mind is caring for other, the individual`s mind may be taken away from own problems. A Nigerian participant who believes that it works for her said:

*I give out a little support almost on every aspect of my life (ht0484fn).*

**Public support:** Beside the fact that social inclusion among other things improves quality of life for PLWHA (Skevington, Norweg, and Standage 2010), providing jobs for PLWHA does even more good. According to a Nigerian participant, the 'sense of purpose' which working gives will go a long way in removing the minds of PLWHA from the disease.

*By employing them you are giving them right to life, because when they, no matter how small the salary is, when they have a job, at least when they are eager I want to dress up and come to work, I want to make an impact in my workplace, their mind is removed from the disease (ht0484fn).*

Another Nigerian participant who agrees with the former said, she had personally received soft loan from her support group which had help her financially and psychologically.

*The support group I always go has helped me a lot – financially, they give us soft loan to upgrade ourselves, then we pay back (aw0071fn).*

**True empowerment:** Socially and financially, empowerment helps PLWHA to gracefully live with the disease. Nevertheless, a Nigerian participant suggests that what PLWHA need is true empowerment rather than what she had often witnessed; that is equipping PLWHA with skills alone which are not enough for meeting their empowerment needs. Therefore, she suggests that they should be established and monitored too.

*Empowerment like those that want to learn hand work, and if they learn the work you establish they. You establish them, you monitor them to see if the business is going. Because there is some of them they will learn the work you won`t establish them, and you say you have empowered somebody. Is just like you send somebody to learn trade and you don't ... they are doing it, in Nigeria they will say they want to empower positive people, they will say they will train you a day or two, the only thing they will give you is your meal for that day. In Nigeria, they are not doing it well enough (aw0071fn).*

**Standby HIV-positive counsellors:** It seems that the PLWHA in Nigeria hardly agitate. The out spoken participant who managed to break the silence suggests that, among the staffs of hospitals and health centres where HIV screening is carried out, there should be employed standby HIV-positive counsellors who will swiftly counsel those who test positive to the disease right at the centres. This agitation is likely because the knowledge alone that the person counselling you is also a HIV-positive individual will go a long way in coping with the initial shocks of being pronounced HIV-positive.

*So is better for a positive person, is he that wears the shoe that know where it pinches. Like in the hospital, that is what we are trying to see if they can do in the hospitals or health centres. Make sure they take positive male or female so that anybody that test positive some will say when they test positive let the grass open let me go in. Immediately they come to you counsel them – when you see that person, you see that the person then disclose, immediately you disclose to that person, the person will calm down, he will know that is not the end of the world (aw0071fn).*

### 4.2.10 Summary of conceptions on coping strategies

A total of 20 themes emerged in this sub-category, (7 and 13 from the Finnish and the Nigerian participants respectively). The 7 themes from the Finnish group are somewhat similar to 7 out of the 13 Nigerian themes. They revealed that testing positive to HIV is not the end of the road, rather by employing the appropriate tools as suggested by both Finnish and Nigerian participants, individuals who test positive to the disease can gracefully cope with it. The tools as they suggested are not taking the disease as a part of one`s everyday life, not being worried about anything, being strong without showing any sign of self-pity, having the desire to live which enables individuals` efforts in fighting back against the forces that accompanies the disease. They also said that esteeming one`s self, having someone to talk to, visiting one another, support group meetings, helping others, and becoming empowered have helped them in one way or

another. Then for the benefit of the newly confirmed HIV-positive individuals, the Nigerian participants believe it is necessary to permanently employ HIV-positive person(s) who will be manned as counsellors at the HIV screening hospitals and health centres. One thing worth noting is that this sub-category is somewhat lengthier than the earlier ones, and that alone reveals that handful of coping strategies were suggested based on the wealth of experiences acquired by the participants over the years. So in this sub-category there a lot that could help PLWHA to better manage their condition especially the newly confirmed individuals.

For further insight, concept maps in figures 13 and 14 below separately mapped out the overall emotional/ mental health impacts of HIV on the Finnish and Nigerian participants, and table 16 in appendix II shows the comparison between the Finnish and Nigerian participants` experiences with the coping strategies, and the comparison was backed with findings from earlier studies. This is the end of the category on 'impacts of HIV on emotional/ mental health' (consisting of 5 sub-categories, 56 themes – 29 and 27 from the Finnish and the Nigerian participants` conceptions respectively). The comparative descriptions in this category reveal that the emotional/ mental health impacts of the disease varied widely between the Finnish and Nigerian participants; however, in some number of occasions they share the same views. The next category explored the 'impacts of HIV on physical health.

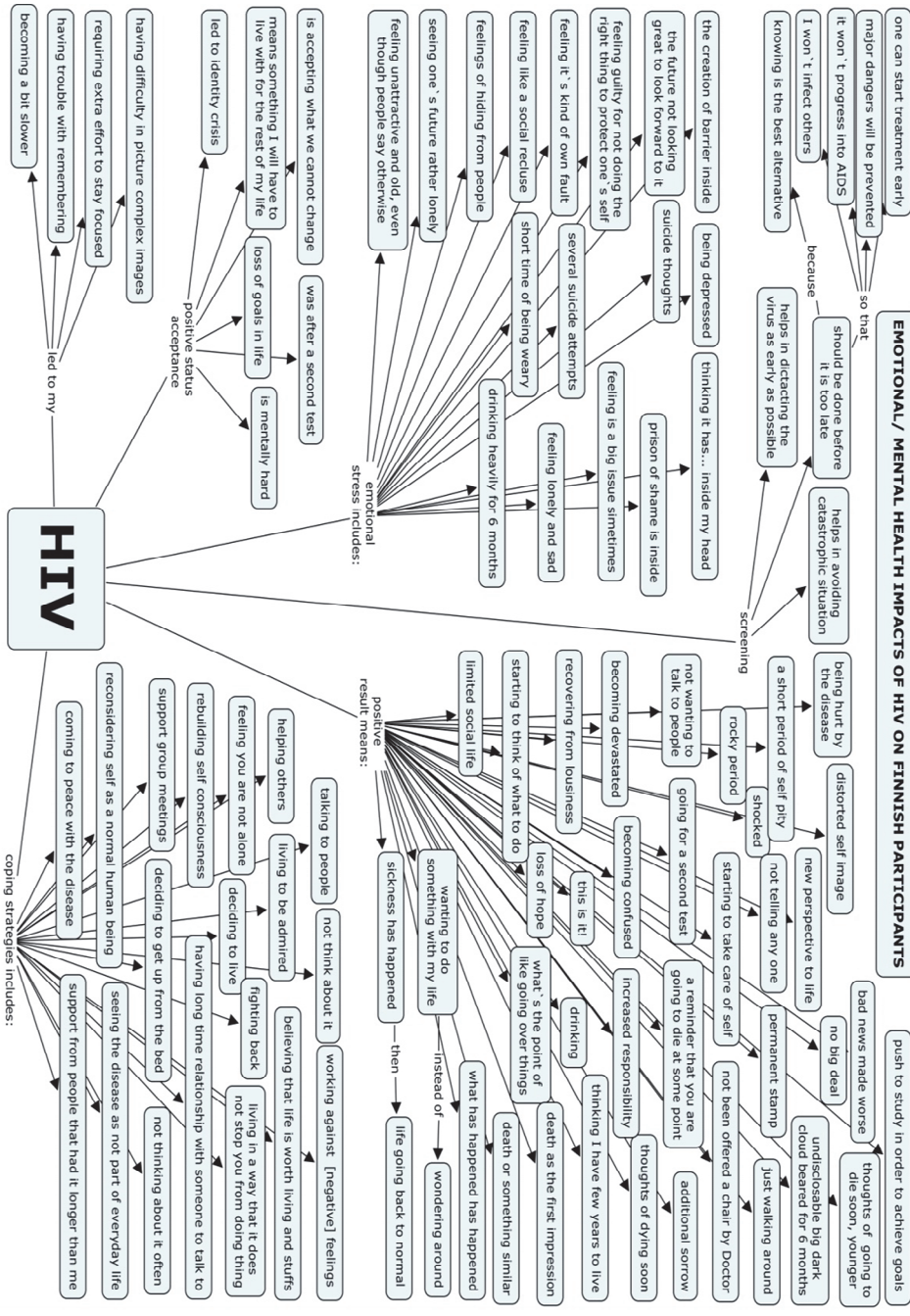


**Figure 13.** Concept Map on the impacts of HIV on the Finnish participants` emotional/ mental health

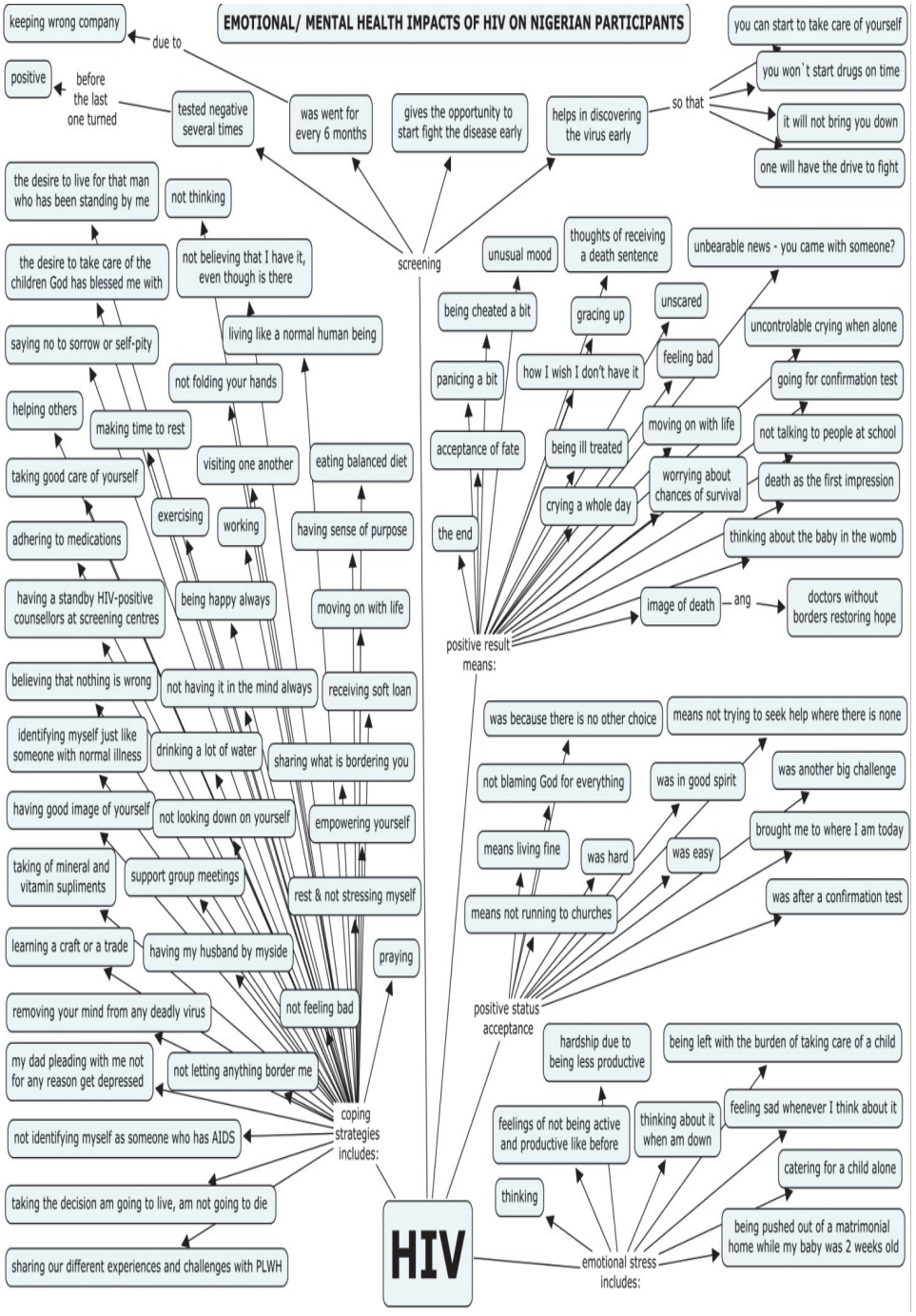


**Figure 14.** Concept Map on the impacts of HIV on the Nigerian participants` emotional/ mental health

## 4.3 Impacts of HIV on physical health

This category describes the physical health impacts of HIV through two sub-categories namely: Physical health conditions and Medical treatments as shown in figure 15 below. Here all the ways the disease has physically affected both groups are explored including the meanings they ascribe to their experiences with HIV medical treatments/medications, and their understandings of it.

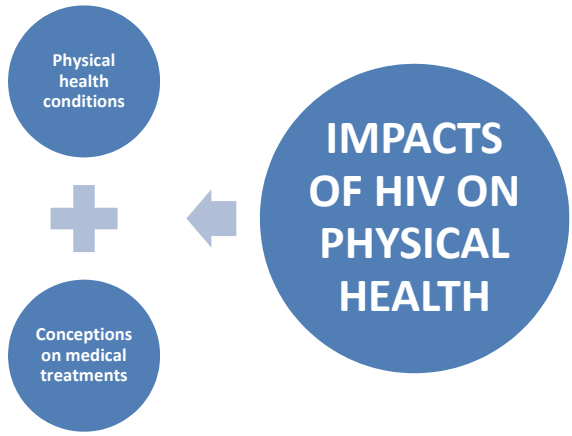


**Figure 15.** The impacts of HIV on physical health

### 4.3.1 Physical health conditions

Based on the experiences and understandings of the Finnish participants, the impacts of HIV on physical health make up the following themes: 'HIV-negative babies, just being chronically ill, low CD4 count, bartered body image, early menopause, and becoming a bit slow'. While from the Nigerian participants emerged: 'HIV-negative babies, healthier than before, looking good without a make-up, low CD4 count, disfigured body, frequent illness, and prolonged fever'. The arrangement of the themes in this sub-category is different; seeing the need to arrange them solely from positive to negative essential.

**HIV-negative babies:** One of the most outstanding good news despite HIV is the decreasing chances of mother-to-child HIV infection. Fortunately, it has never been experienced by any of the participants of this study. Two of the Finnish participants have HIV-negative children, and the one who has none yet, is less troubled by that because she is aware that in Finland 100s of HIV-positive women have given birth to HIV-negative children.

> *I know that in Finland I think that there have been 100 or something positive women that have given birth and all the babies have been health, so I know that that is not the problem (sh0485ff).*

Likewise the Nigerian participants, three of them that are married gave birth to HIV-negative children, one of them said:

*...so right now am married to someone who is not HIV infected, and also I have two children who are not HIV infected (ht0484fn).*

**Healthier than before**: Surprisingly, a Nigerian participant who believes that living with HIV has not done her any harm said she is even healthier than before.

*Even if I have HIV, does it show in me? So far as it does not show in me, so am fine. Am even more healthy than before (as0481fn).*

Perhaps this is because the availability of HIV/AIDS treatments is improving quality of life in the PLWHA (Beard, Feeley, Rosen 2009) as elaborated in the next sub-category.

**Looking good without a make-up:** In the present world where people spend billions of dollars in search for what I will call "cosmeticated beauty", a Nigerian participant who was once very sick now believe that she is so well that even without a make-up she still looks beautiful.

*Then I was very sick I could not even fight back anything that get on my way, but as you can see, am sure even without the make-up or things like that am looking good. Nothing, nothing bad about my health (ht0484fn).*

**Just being chronically ill:** Many studies have shown that in order to minimise the weight of the disease, PLWHA tag themselves as just being chronically ill. For instance, in Anderson and Spencer (2002, 1345) one participant said, *"I try not to let it bother me because my viral load and everything is real low...."* Similarly, seeing herself as one who is only chronically ill, a Finnish participant said:

*If I fall ill, I will need help, but I don't think I'll be more dependent on health care than other cronically ill. I can travel to 3.rd world countrries as long as I'll have my supply of medicine with me (ms9367ff).*

Another Finnish participant believes that though living with HIV has affected her health, it has not made her sicker.

*...obviously it has affected my health because I have HIV, but at least at this point because I have had it for 7 years now, I don`t am not any more sick than I was before (sh0485ff).*

**Low CD4 count:** CD4 is part of the body immune system. As argued by a Finnish participant, its ideal count is between 750 and 1500; and whenever it is lower than normal in an individual, the person will become prone to opportunistic diseases. Unfortunately, since HIV is a disease of the immune system, PLWHA seems to be at greater risk of having low CD4 count. Recalling from her experience, a Finnish participant said:

*My viral load even when I was diagnosed was really low, that`s good thing, even when I was diagnosed my CD4 count was then like – I don`t remember,*

*was really low, like the starting point ...what am trying to explain is that even normal people that don`t have HIV, your CD4 count should be in between 750 and 1500 I don`t know ...so my CD4 count went somewhere around 300, so then we decided that I should start, otherwise my viral load is still really low, but the CD4 count is what they are like looking ...if I would have had 1500 when I got diagnosed, it would have taken more time, so (sh0485ff).*

Three of the Nigerian participants also narrated their experiences with low CD4 counts. Like their Finnish counterparts, they all began to take HIV medications after their CD4 counts were diagnosed low.

*...when I went there I never started taking drugs, but when it get to a stage, they will check your CD4 count, if it is low you will start taking drugs, is the doctor that will recommend a drug for you (as0481fn).*

*They carried a test on me, and I was still doing very well, my CD4 count back then was still about 80 (800) something, I didn't need to start ARV immediately (tp0389fn*).

*I was really down then, I cannot even walk then. My CD4 was very low, very low, almost at the point of death (aw0071fn).*

**Bartered body image/ Disfigured body:** A Finnish participant who had lived with the disease for about 20 year said the disease and its treatments has bartered her body image so much so that she now looks like a pregnant woman when she is not.

*All the fat has disappeared from the face and limbs and accumulated int the waist area. It looks like I am pregnant. My tummy is upset at times (flatulence and diarrhea), I have nightmares, rashes and have had several allergic reactions for the drugs they have used on me (ms9367ff).*

Her Nigerian counterpart with similar experience and had lived with the disease for about 13 years said:

*...the effect was it make your chick go inside, your knee will go inside, even your bombom (buttocks) will go inside that was how it was. And my stomach was big as a pregnant woman (aw0071fn)*

**Early menopause:** The same Finnish participant also thinks that her menopause at 45 came remarkably early, and she believes that it happened because the HIV medications she has been using destroyed her testosterone.

*I am 45 and my menopause has showed some signs of starting remarkably early... because the drugs eat away my testosterone (ms9367ff).*

**Becoming a bit slow:** Furthermore, the same Finnish participant sees the disease as the cause of her being slower than normal. She also has problem with staying focused, troubles with remembering things, and difficulties with picturing complex images.

*I have trouble remembering, I am a bit slower and it takes an extra efford to stay focused and to picture complex entiretys (ms9367ff).*

**Frequent illness:** Malaria remains a deadly disease in Sub-Saharan Africa and kills thousands of people every year, but because of its rampancy in Nigeria, it is often call 'common malaria'. PLWHA are at increased risk of clinical malaria, severe illness, hospitalization, and death (NMFS 2011). Narrating from her experience even before her HIV diagnosis, a Nigerian participant said she has always been prone to malaria due to her AA genotype.

*Before I tested positive, I rarely fall ill, but the malaria thing kept coming you know in all I do. I take immune booster, minerals; I don't stress myself I rest.... Am AA (genotype) with the way I am, being AA am very prone to malaria HIV positive or not. I have met people who treat malaria every two to three weeks, and they are negative, so I don't fall sick often because I am positive (tp0389fn).*

**Prolonged fever:** Many of the PLWHA in Nigeria and their families are often frustrated with the challenges of managing the disease (Ogunjuyigbe, Adeyemi & Obiyan 2009) probably due to the disease`s influence in prolonging fever. Narrating her earlier experience, a Nigerian participant said:

*I was reducing in weight. Malaria, headache, then I had a very long hair, I had to scrape off the hair.... Normal persons, their malaria can take a day or two to go, but our own since own immunity is not that okay, it can take about a week before we are okay, then the whole system will come back to be better again, so is not very easy (aw0071fn).*

### 4.3.2 Summary on physical health conditions

In this sub-category a total of 13 themes (6 and 7 from the Finnish and the Nigerian participants respectively) emerged reflecting the physical health conditions of the participants. On three occasions the two groups shared similar views, while on others they differed. The arrangement of the themes took a different approach in order to uphold presenting all the positive responses first. The participants demonstrated no fear of giving birth to HIV-positive children, and the children they already have are all HIV-negative. In addition, two of the Nigerian participants positively sounded alike; while one said she is even healthier than before, another said she now appears pretty even without a make-up. A Finnish participant who somewhat sounded similar said, she sees herself as one who is only chronically ill. But prior to their being prescribed HIV medications, some of the Finnish and Nigerian participants were diagnosed with low CD4 counts. Then while one Nigerian participant remembered experiencing frequent illness, another recalled suffering prolonged fever.

One Nigerian of the participants who have lived with the disease for about 13 years said, it has disfigured her body by making her chicks, knees and buttocks go inside, and her stomach swollen as though she is pregnant. Her Finnish counterpart who had lived with the disease for about 20 years with similar experience said she now has bartered body in the sense that all the fat in her face and limbs seems to have moved to the waist area making it look as if she is pregnant when she is not. Then at 45 she is already seeing signs of her menopause which

she believes are due to HIV medications which had destroyed her testosterone. She also believes that the disease (or better still its medication) is responsible for her being slower than normal, has problem with staying focused, has troubles with remembering things, and has difficulties with picturing complex images. On the overall, the Finnish participants expressed slightly greater bitterness over their physical health conditions than their Nigerian counterparts.

For further insight, concept maps in figures 16 and 17 in pages 113 and 114 separately mapped out the overall physical health impacts of HIV on the Finnish and Nigerian participants, and table 17 in appendix III shows the comparison between the Finnish and Nigerian participants` conceptions on the impacts of HIV on their physical health conditions, the comparison was backed with findings from earlier studies. The next sub-category explored the participants` experiences with HIV medical treatments.

### 4.3.3 Conceptions on medical treatments

Early treatment is essential for the better management of HIV, or in order to prevent it from progressing into AIDS. But unfortunately those who tested positive to HIV in the early 1980s had no such privilege because it took some couple of years after the discovery of HIV/AIDS before appropriate medications were found. Later the combination of different antiretroviral medicines known as 'HAART (highly active antiretroviral therapy)' was introduced to further slowdown the multiplication of HIV virus in the body. Many experts argue that, since the introduction of Anti-Retro Viral (ARV) drugs, HIV progression in human body has greatly slowed down (WHO 2010b), and the health of PLWHA significantly improved.

However, beside the main effects (i.e. slowing down the multiplication of HIV virus), it has been reported that ARV or HAART have had side-effects on some of their users, and in some occasions fatal, leading to change of medications. In this sub-category, the experiences of participants with HIV medications have been explored and compared. As outlined from their responses, the themes under which the Finnish participants` experiences were discussed are: 'regular check-up, daily swallowing pills, boosting immunity, wired side-effects, lesser side-effects, and vaccination seems uncertain', while that of the Nigerian participants are: 'regular check-up, adherence to doctors` prescriptions, limited medication and treatments, change of medication, and rumours of a cure'. Here the themes are also uniquely presented; the main effects of medical treatments were presented first, and later the side-effects.

**Regular check-up:** Due to negligence on one hand, and the high cost of medical treatments on another, many overlook the need to regularly go for a medical check-up. But to the participants of this study, testing positive to HIV has given them the opportunity to regularly go for free medical check-up which among other benefits enables early dictation of other emerging diseases. Two of the Finnish participants describe the opportunity thus:

*...now is just every three months I go to the doctor (sh0485ff).*

*...because I have to go see doctor every 4, 5 or 6 months, am under this intense scouting, you know it`s, that positive side is if I will get any other disease, it will be detected very early, at the very early stage (sn9975ff).*

For three of the Nigerian participants, the privilege cannot be over emphasised which they expressed thus:

*...is an advantage, is an advantage, even if I have any disease the doctor will know. Time to time, there is a limit to anything, when it get to some time you are taking your drug, maybe some months, they will ask you to go for some test, if you have any disease, the test will carry it out (reveal it). Because the drugs too always, it might have side effect. That is how the doctors always care for, they will place you on test always, if there is any problem they will tell you (as0481fn).*

*I think is an advantage, visiting the hospital frequent is good for other things to be detected. Like I could visit doctor monthly and he run some tests. Some three months, some six monthly – twice a year. For me is an advantage because ordinarily, this is Nigeria let's be realistic, some people will not even see a doctor for years they will say nothing is wrong with them. So for me that is also an advantage (ht0484n).*

*They have done series of test to see if there is any other infection that you have, then they will treat that apart. There is this savica (cervical) cancer screening they were doing for the women; at list it was an opportunity. I went for the test, they have to test my womb to see if there is anything like cancerous something there. It gives you, it is a way to see if there is any other disease in your body, they will detect it and they will treat it (aw0071fn).*

**Daily swallowing pills/ Adherence to doctors` prescriptions:** Counting it as a duty to swallow her pills daily, a Finnish participant said she adheres to her HIV medication.

*I have to take my medication everyday same time, so is up to me (sh0485ff).*

All the four Nigerian participants emphasised the need for one to above all odds adhere to doctors` prescriptions. The one who sees is as an opportunity to extend life said:

*When you are on the drug taking it regularly, the way the doctor – adhere to your treatment, you will live longer (aw0071fn).*

Another who is now accustomed her medications adherence said:

*It has got to a stage I just have to. If I don't take my drugs I won`t feel free. Maybe I mistakenly did not take it, I will not get myself through that day, so is part of me, I never even want to try and careless, that is why I always have alarm to remind me of it morning and night. Once my alarm ring I stood up and take it immediately (as0481fn).*

Another whose counsellor advised to yearn for her medications as for food said:

*From what my counsellor told me 'just feel like you have to eat, no one can go a day without food'. So the same thing apply to the drug, I can`t do a day*

*without it. Well am on two combinations, I take one twice a day, and the other one once a day (tp0389fn).*

Then the fourth who initially found it very challenging to adhere said:

*At the initial time I was worried, but my husband, even the children they always, at time the alarm will be ringing and I will forget, is the children that will mummy mummy is time for your drug. That is why they always tell us in the hospital, choose a treatment partner, tell somebody that will always be reminding you about your drug. The thing is now part of me (aw0071fn).*

**Boosting immunity:** The most significant impact of HIV treatments is that more PLWHA are alive and coping with the disease (Clarke 2004). Echeverria, Jonnalagadda, Hopkins and Rosenbloom (1999) associated PI (protease inhibitor) treatments with weight gain, deceased viral load, increased CD4 counts, fewer opportunistic diseases, and better quality of life. As such, for a Finnish participant, HIV medications mean boosting her immunity. As she explained it, her CD4 count that should be about 700 went as low as 100, but her medications normalised it.

*Because my immune system (CD4 count) was low, but with the medication it is normal again, it was between 100 and 200 I think, it`s now I think 700 (sn9975ff).*

**Wired side-effects/ Change of medication:** Except for placebos (i.e. non-medical substances given to reinforce patients` expectation to get well), all medications are fill with chemical substances which produce effects. The expected positive effects are called 'main effects', while the adverse unwanted ones are called 'side effects' and the later put patients in harm's way. So, as the ARV or HAART when used produce main effects, they also in some cases produce side-effects (NordPol 2007), which have led to profound weight loss, reduced quality of life, and missing of doses (Douaihy and Singh 2001). The medications may also cause illness, fatigue, depression, and chronic disability (Clarke 2004). So due to ARV`s possible side-effects, Zimmet (2005) advises that caution should be taken before prescriptions are made. Accordingly, a Finnish participant who has been on HIV medication for 15 years, the drugs has not only placed a permanent dent on her health, but has also disfigured her body.

*The modern combination drugs are making me tired and affect my body. They have all kind of weird side- effects. All the fat has disappeared from the face and limbs and accumulated int the waist area. It looks like I am pregnant. My tummy is upset at times, I have nightmares, rashes and have had several allergic reactions for the drugs they have used on me. Some of them so severe, I had to be rushed into hospital because I could not breathe (ms9367ff).*

Another believes that she might need to change her medication at some point in order overcome the tricky nature of the disease.

*...maybe at some point I might have to change my drugs ... it`s very tricky, you just have to be one step ahead of it (sh0485ff).*

Three of the Nigerian participants also see on the need to switch from a particular medication at some point. One judging from a personal experience with body disfiguration said:

> *The first one there was, the first one I took, the first combination I took, the effect was it make your chick go inside, your knee will go inside, even your bombom (buttock) will go inside that was how it was. And my stomach was big as a pregnant woman, so when I complain it was there they told me it was the effect of the drug. So they had to, the only thing they had to do, change the, remove that emm emm (tried in vain to remember the name of the drug which was replaced), and put another one. Some might have rashes all over, and some people it doesn't affect them. This one am taking now, another thing am noticing is that it use to reduce your (my) blood level. Last month, the time I was sick, I noticed it my blood dropped, so I had to buy multivitamin (supplements) and vegetable to build it up (aw0071fn).*

Another also stating that side-effects may lead to replacement of a given medication said:

> *If they give you the first stage, if it don't have, if it has side-effect, they will ask you to come back to the hospital, they will give you another one. I never have any side effect since I have been taking it (as0481fn).*

Then the third who counts herself lucky for having not experience any side-effect like others said:

> *When theirs are giving one problem by the time they are placed on another drug is too late and things like that, but for me once they placed me on drug, within a year, within 6 months my viral load has reduced to what we call 'undetectable'. And I have been, I don't have any drug reaction, thing of such I have never seen. I don't have any drug reaction or whatsoever, I will say thank God (ht0484fn).*

**Lesser side-effects:** One of the Finnish participants who believes that HIV medications are becoming better said that their side-effects are also becoming less.

> *I think the treatment, you know I think the treatment now is really good, you know you can now live good healthy life, and side-effects of the medications are getting less and less all the time (sn9975ff).*

**Vaccination seems uncertain:** There is no sure vaccine or recognised cure for HIV/AIDS (Ristola and Sutinen 2002). Although efforts are being made on finding a vaccine for HIV, there are still hinderances. But lands mark are being made; at present, the 44% to 73% capacity of Truvada (the first FDA approved drug for HIV prevention) to prevent HIV remains unsurpassed (BBC May 2012). Nevertheless, to a Finnish participant, the sure vaccination she recommends is equipping people with valuable information on the disease.

> *I don't know a lot about it, but I know is very hard to find it. And I know that there has been some vaccination, there have been some research somewhere in Africa, and it has minimised the possibility of getting the disease*

*40% or something. I really think like safe sex and clean needles, needles protection proper, they are the best vaccination, 40% is not, I don't think before companies come with this 100% vaccination, maybe we should put more money on information and you know helping to stop it in other ways you know (sn9975ff).*

Another who is less optimistic because a head doctor she knows does not want to give false hope still believes that stem cell treatment may bring the long expected hope.

*The head doctor at Helsinki's infectuous diseases unit was not too optimistic about it, quess he did not want to give us false hope. The stem- shell treatment might be a solution! One day soon the serum will be found and a vaccine developed. Maybe those children born to us positive have got something in their system that could help (ms9367ff).*

Then the Nigerian participants` views on HIV vaccines ranges from haven not heard about it to the knowledge they are available.

*No I have not heard about it (as0481fn).*

*I have heard it, but I don't know much about it (ht0484fn).*

*There are vaccines now that will help [control] the infection, like for instance I want to get married to – my partner is negative, that vaccine will help prevent my infecting him, of course I want to get pregnant (tp0389fn).*

**Limited medication and treatments:** While the Finnish participants say they are receiving all the medical treatments they need, one of the Nigerian participants lamented about the rationing of ARV in Nigerian due to its scarcity. She also said unlike before, the challenge of footing other medical expenses now rest on them, and as a result many who cannot afford it are dying. To her, thing are getting worse primarily because the foreign donors are fast withdrawing their supports.

*Like now at times in the hospital, they only give us the ARV, other drug we buy that is what is, unlike before, if we have malaria they give us the drugs free, but now is only ARV... now if you have malaria you go to the hospital, they will just prescribe for you, they will say is out of, everything go and buy.... The test, x-ray and everything, if it was like before, they will run the test for free.... At times you will see them rationing the ARV – the drug they give us. If you are to collect your one month drug they will share it so that another person will get. Since last year we are losing a lot of people, people are dying – those that are tested, those who cannot afford to take care of themselves, it can be a little cold , like our malaria is different from a normal human-being.... some of the donors, those that are supporting us have started withdrawing. Those foreign donors that are helping us with our drugs and treatments; that is why we are finding it difficult in the hospital now, and government is not doing enough, now anything go and buy (aw0071fn).*

**Rumours of a cure:** The progression of HIV in the body can be slowed to a near halted with HIV treatments (WHO 2010b), but there is no known cure.

However, some of the Nigerian participants believe that there is already a cure for the disease which unfortunately has not reached Nigeria because private hospitals make a lot of money from HIV medications. The two Nigerian participants who expressed this view said:

> *...as we are hearing, as we are hearing these days, we heard that the cure has come out some places outside Nigeria, all these European countries, the cure has come, but it has not entered Nigeria. You know if you go to some places you will be hearing all these sort of thing. You know why they don't want it to come to Nigeria is because they (private hospitals) are making a lot of money through this drug they are selling (aw0071fn).*
>
> *...as a matter of fact I heard there is a cure in Europe that is what I heard. It has not come down to everybody now, but I heard there is a cure (tp0389fn).*

### 4.3.4 Summary of conceptions on medical treatments

A total of 11 themes (six and five from the Finnish and the Nigerian participants respectively) emerged in this sub-category expressing the participants` experiences with medical treatments. The responses revealed a number of health advantages the PLWHA are enjoying unlike those who are either HIV-negative or those who have not discovered their HIV-positive status. For instance, many who ought to visit the hospital on regular bases for check-ups and early detection of diseases do not do so due to high cost of medical services and personal negligence, but living with the disease had been compelling the PLWHA in Finland and Nigeria to get their systems regularly checked. But while it has remained at no cost for the Finns, the trend in Nigeria has been changing for the worse, and the PLWHA in Nigeria have not been finding it funny. But despite all the odds, the participants especially the Nigerian believe it is essential to adhere to one`s medications which has contributed greatly to restoring their health. Nevertheless, a Nigerian participant lamented that their immediate challenge is that while they are now being forced to pay for other treatments beside ARV, even the ARV is now rationed due to its scarcity.

But the most outstanding worries about the medications are their side-effects. Particularly, the Finnish and Nigerian participants who have lived with the disease for 20 years and 13 years respectively, they said the HIV medications they used have among other effects disfigured their bodies. But a Finnish participant believes that the side-effects of HIV medications are becoming less. Then though up to 73% prevention can be achieved through a newly approved HIV drug, a Finnish participant believes that the best HIV vaccination is to further educate people about the disease. Furthermore, while the Finnish participants are not very optimistic about a HIV cure in the near future, the Nigerian participants believe that there is already a cure for HIV in Europe, but the private hospitals in Nigerian have been preventing it from reaching the country because they make a lot of money from the ARV. Here there is no much difference in the two groups` responses; on the overall, it seems while the Finnish participants are more up to date, their Nigerian counterparts are more optimistic.

For further insight, concept maps in figures 16 and 17 below separately mapped out the overall physical health impacts of HIV on the Finnish and Nige-

rian participants, and table 18 in appendix III shows the comparison between the Finnish and Nigerian participants` conceptions on HIV medical treatments, and the comparison was backed with findings from earlier studies. This is the end of category three on the physical health impacts of HIV (consisting of 2 sub-categories and 24 themes – 12 each on the Finnish and the Nigerian participants` conceptions); the next category explored the participants` experiences with social health impacts of the disease.

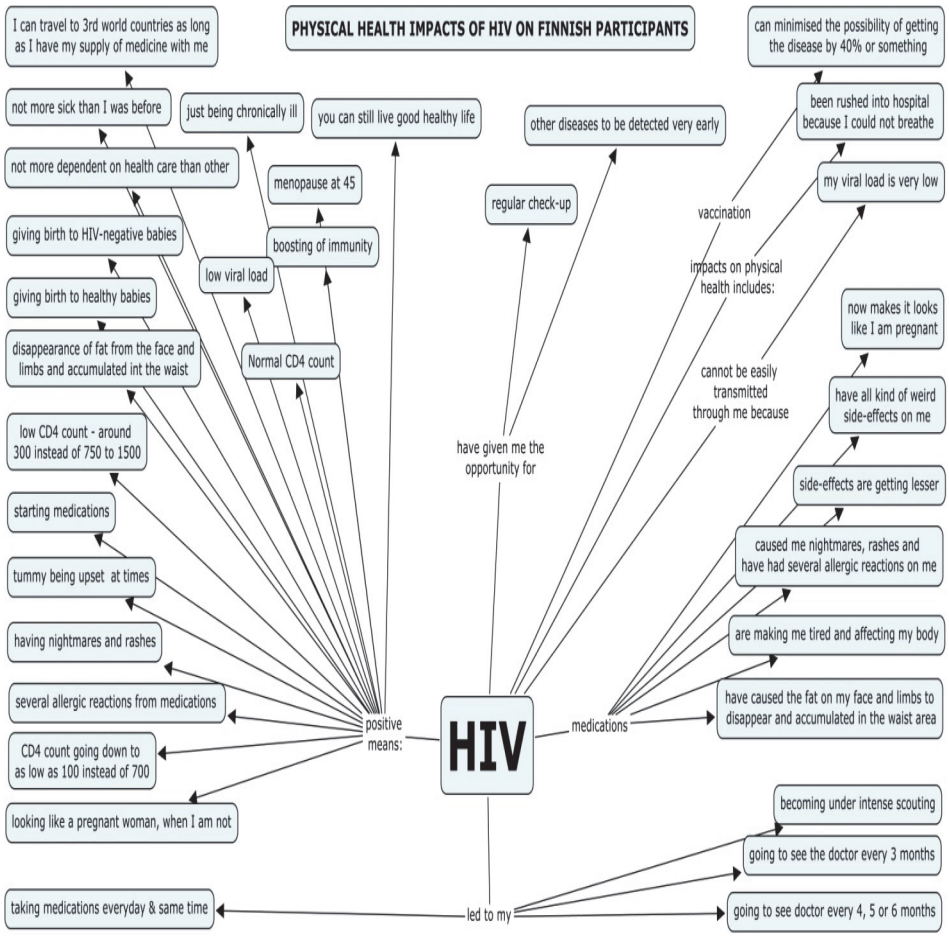


**Figure 16.** Concept Map on the impacts of HIV on Finnish participants` physical health

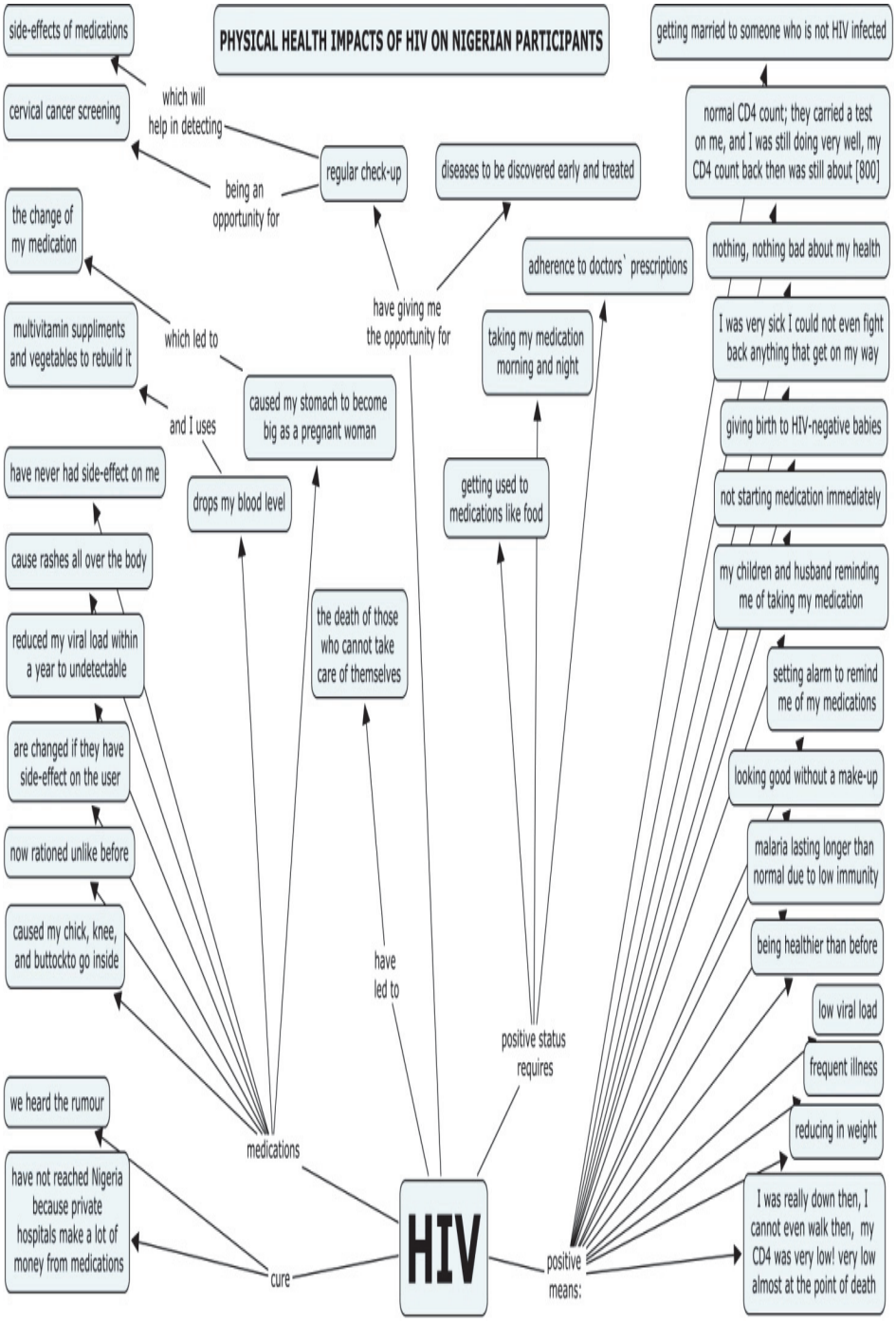


**Figure 17.** Concept Map on the impacts of HIV on Nigerian participants` physical health

## 4.4 Impacts of HIV/AIDS on social health

This category describes the social health impacts of HIV/AIDS through five sub-categories namely: Opportunities forgone, Disclosure of positive status, HIV stigma & discrimination, Impacts on relationships, and Impacts on faith & spirituality as shown in figure 18 below. Here all the ways the disease has socially affected both the Finnish and Nigerian participants were explored based primarily on the meanings they ascribe to their personal experiences.

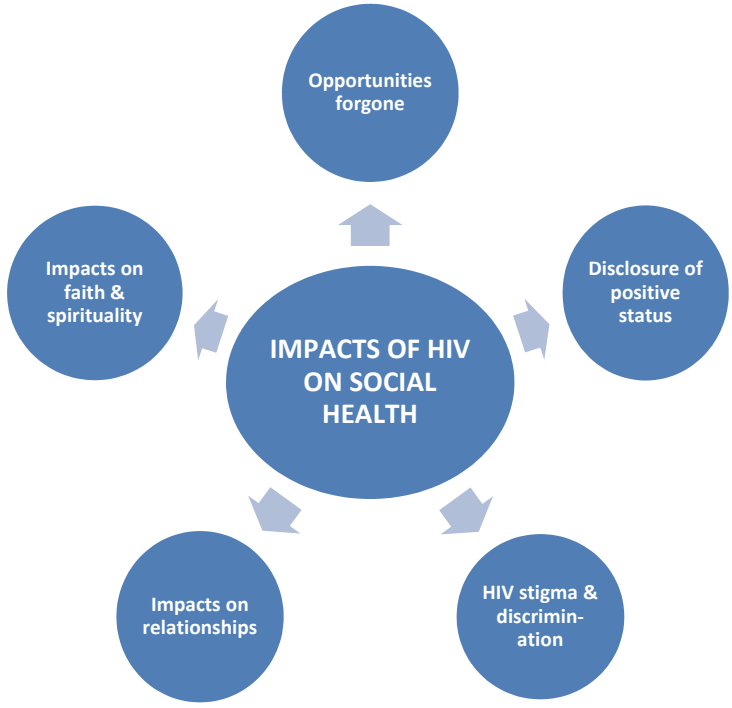


**Figure 18.** Impacts of HIV on social health

### 4.4.1 Opportunities forgone

Financially, HIV/AIDS costs a lot, but besides the financial costs, once a person tests positive to the disease, some aspects of the individual`s life becomes permanently changed making the individual to completely forgo some number of opportunities. In this sub-category, the opportunities forgone due to testing positive to HIV have been explored based on the experiences of the Finnish and Nigerian participants. The themes under which the Finnish participants` experiences were explored are: 'no career in public service, no thanks to cheaper school health care services, unfulfilled dream of a second child, constant use of condoms, and no to breastfeeding, not getting pregnant in the normal way'. While that of the Nigerian participants are: 'Change to a career in Social Work,

no career with private schools, loss of opportunity for a third child, frequent use of condoms, and no to breastfeeding'.

**No career in public service/ Change to a career in social work:** For the fear that her positive status may leak, a Finnish participant said she would not want to pursue a career in public service. Although she is not sure if she has had such interest, but to her one thing that is certain is that the opportunity no longer exist.

> *I will never, I wouldn't want to pursue job or position where I would be public person, because I wouldn't want, I wouldn't want where all this thing all this to come out you know, I don't know if I would pursue it if I didn't have this disease, but now am sure I wouldn't do it, so in that way – yes (sn9975ff).*

But on the contrary, a Nigerian participant sees living with the disease as a reason to abandon her career in mechanical engineering and pursue another in social work.

> *I did MD in mechanical engineering, so when HIV came into my situation in the sense that is not as if engineering is not a fine course, but I felt like going to talk to people, going to socialise, am going to go into social work, that is why am doing social work now. For me is an opportunity to do so many things, so for me sociology is a fine course (ht0484fn).*

**No thanks to cheaper school health care services/ No career with private schools:** In Finland unlike in Nigeria, students enjoy a lot of benefits which includes cheaper health care services, but in order to give no room for anyone within the walls of her school to know that she is HIV-positive, a Finnish participant chooses to put her opportunity for receiving cheaper health care services on the line.

> *Well, that is why I don't go to, you know student health care, I don't even want to tell them there. Otherwise I know is something they can`t, - is cheaper I know they have to keep silent about it, but I still don`t wanna go there (sn9975ff).*

While living with HIV is a reason for a Finnish participant not to consider a career in public service, for a Nigeria participant who is a teacher by training, the case is somewhat different; for her living with HIV is actually the reason not to accept an offer to teach in a private school because private school [being an entrepreneurship] may not give her the frequent off days she needs to attend to her health.

> *At times when it border me is now if am teaching with a private this thing (school) tomorrow you say you are going to the hospital for your clinic, next tomorrow you say you will be going to another (aw0071fn).*

**Unfulfilled dream of a second child/ Loss of opportunity for a third child:** While to a Finnish participant living HIV has stolen her dream of giving birth to a second child.

*I have deamed about having another child before it is totally too late for me (ms9367ff).*

To her Nigerian counterpart, the disease took away her opportunity for a third child.

*It haut me, I wanted to have another child, when that my daughter was 6 year old, she is 12 now. My husband said "no because of your health, I don't want a situation where you will have another child and be down..." not even the negative children but my health, my health that matters (aw0071fn).*

But for another Nigerian participant the hope for a third child is still alive.

*Even before I knew my status, I will say I want to have three children, I have two now and one will come later (ht0484fn).*

**Constant use of condoms/ Frequent use of condoms:** Unlike before she tested positive, a Finnish participant now constantly use condoms because she does not want to infect her HIV-negative boyfriend.

*Obviously we don`t want to have sex without condom because I don`t want to infect him (sh0485ff).*

But for a Nigerian participant who is married to a HIV-negative husband, they use condoms but not always. She said they do take the risk because her viral low has been reduced to undetectable; nevertheless, it is not without medical counsels.

*We use condoms. We don't use condoms all the time, we also have inter-course without condoms, he knows my viral load is low – 'undetectable', still we use condoms, but we are taking that risk, he also sees the doctor because you can`t do it alone. When you have HIV you can`t have your baby alone you have to like seek medical advice from the professionals (ht0484fn).*

But another Nigerian participant pities her husband whom she believe does not get sexually satisfied because they constantly use condoms.

*At times I feel, at times I pity the man. He might not want to use the condom, like Nigerian, African mentality. At times I feel for him, at times I feel that condom he might not be satisfy, but there is nothing he can do, just to protect himself (aw0071fn).*

**No to breastfeeding:** Another opportunity the Finnish and Nigerian participants had to forgo is breastfeeding their babies. They were advised not to in order to avoid infecting their babies through breast milk. A Finnish participant stated it thus:

*...no breastfeeding, I did not, as I was told that there are risks (sn9975ff).*

While a Nigerian participant puts it this way:

*I did not breast fed, she was already on baby formula, hustling here and there (aw0071fn).*

Nevertheless, in Nigeria where breastfeeding is seen as an essential duty of a mother, another Nigerian participant believes that not breastfeeding her baby is actually the reason why her first husband who against their doctor`s advice was making love to her without condoms threw her out of his house. She also believes that family pressure may make it her most outstanding challenge in her present marriage, however.

*I won`t say my first husband left me because of that because the doctor call him not to make love with me freely, but he does that. He said he cannot use condom with his wife. I will say maybe is because family issues, because I couldn't breast feed. But I know more challenges are still coming, am talking about the second husband I have married, I know am still going to face a lot of challenge. You know by the time I have child now, you know I will never want to breast feed, then I will have challenges, the family will challenge me. Am going to face challenges for that, and I know no matter what, God will see me through, I know God will help me out (as0481fn).*

**Not getting pregnant in the normal way:** For one Finnish participant, because her boyfriend is HIV-negative, she believes that she is not going to get pregnant in the normal way; but instead will need a medical assistance.

*Because my boyfriend isn`t HIV-positive so is much easier because well if I, obviously I just can`t get pregnant in the normal way, it doesn`t work like that I know it, but I have to start planning, tell my doctor (sh0485ff).*

### 4.4.2 Summary of opportunities forgone

This sub-category consists of a total of eleven themes (6 and 5 from the Finnish and the Nigerian participants respectively) showing the opportunities the participants have to forgo due to their HIV-positive status. Starting with a Finnish participant; for the fear of her positive status getting leaked to the public, she believes that her opportunity of working in public service no longer exists. But on the contrary, her Nigerian counterpart sees being HIV-positive as a good reason for abandoning a career in mechanical engineering to pursue another in social work. Again, while a Finnish participant sees the disease as a reason for forgoing cheaper school health care services in order to further minimise the chances of her positive status getting leaked to her colleague. Another Nigeria participant who is a teacher by training sees living with HIV as the very reason why she will not want to accept an offer to teach in a private school because it may not give her the frequent off days she would need for attending to her health.

Then while the dream of a Finnish participant to have a second child has been taken away by the disease, the dream of her Nigerian counterpart to have a third child has also been ruined by her positive status. Nevertheless, the hope of a third child is still alive for another Nigerian participant. Furthermore, unlike before she tested positive to HIV, a Finnish participant now constantly use condoms because she does not want to infect her boyfriend. But her Nigerian counterpart occasionally does not use condoms with her HIV-negative husband because she believes that her viral low has been reduced to 'undetectable' which

has reduced her chances of infecting him. But another Nigerian participant pities her husband whom she believes does not get full sexual satisfaction because they constantly use condoms. The Finnish participant whose HIV status differs from that of her boyfriend also believes that she is not going to get pregnant in the normal way because of her positive status and as such, would need medical assistance for that.

Both the Finnish and the Nigerian participants believe that their opportunity of breastfeeding their babies have also been lost. One of the Nigerian participants believes that not breastfeeding her first baby was the main cause of her been thrown out by her first husband, and now it constitutes the major challenge before her in her present one. Except for one (not getting pregnant in the normal way), there is almost one-to-one concord between the two groups` themes. On the overall, it seems there is no wide gap in the opportunities the Finnish and Nigerian participants have forgone.

For further insight, concept maps in figures 19 and 20 in pages 143 and 144 separately mapped out the overall social health impacts of HIV as experienced by the Finnish and Nigerian participants, and table 19 in appendix IV shows the comparison between the Finnish and Nigerian participants` conceptions on the opportunities forgone due to their HIV-positive status, and the comparison was backed with findings from earlier studies. The next sub-category explored the participants` experiences with disclosing their HIV-positive status.

### 4.4.3 Disclosure of positive status

The anticipated negative or positive reaction influences the disclosure of a positive status (Kimberly, Serovich, & Greene 1995). This sub-category explores the experiences of the Finnish and Nigerian participants on disclosing their positive status. From the Finnish group, these experiences have been explored under the following themes: 'open-ended disclosures, repeated disclosure, don't tell at workplace, a nightmare, private thing and drawing people closer'. While that of the Nigerian participants are as follow: 'open-ended disclosure, disclosing to spouse, disclosing to a church member, disclosure at workplace, public disclosure, and keeping hope alive'.

**Open-ended disclosures:** HIV being a disease that is not generally accepted in any society, the PLWH often hide their status from friends and family members, but on rare occasions it is revealed to some especially their partners who act as a source of strength (Clarke 2004). Just like many other themes used in this study, I coined out this caption – 'open-ended disclosure' to express that the participants whose comments are analysed here have been disclosing their status, but only to a selected few. The reason for that is to be somewhat protective on one hand, and yet open doors for much needed supports and interventions. A Finnish participant states it thus:

> *Am afraid of rejection... I have some relatives that don't know about it, and I don't just find any reason why I should tell them, but there are lot people who know about it, my family, closest friends, and then people in NA (Narcotics Anonymous), but still is something I want to keep to myself (sn9975ff).*

One of the two Nigerian participants who claimed they are also doing selective disclosure immediately informed a sister who is closer to her, but her elder sister was not told until recently because she was afraid that she might reveal her status to the world. She also said she studies people before disclosing to them.

*The sister that has been on my side, immediately I got tested positive I told her, but my senior sister it was last year I just told her, but the one that has been, my sister can keep [secret]. So you study people before you disclose (aw0071fn).*

The other disclosed to her entire family members, and also to a selected few among her Muslim sisters, and has never been discriminated for that.

*When I had it I told them, my mum cried, my elder sister cried. My brother called me and told me not to cry, only God knows why it happened, I should feel free.... Only some of my fellow Muslim know, they even give me their baby, carry my baby, we stay together, share food together (as0481fn).*

**Repeated disclosure/ Disclosing to spouse:** The disclosure of a disease such as HIV/AIDS may be more stress inducing than relieving (Serovich, Kimberly and Greene 1998) due to some unprecedented embarrassments. A Finnish participant feels that she is frequently embarrassed by having to reveal her positive status every time she visits a health clinic. She is even further grieved because the treatments for which she makes all the disclosures have nothing to do with HIV.

*At health clinic or something if am treated for something completely, some other thing that is not related to this thing anyway, and for some reason I feel like I have to tell about this as well, I find that quite shameful (sn9975ff).*

But a Nigerian participant acknowledges that although disclosing to a spouse – especially to a male spouse is not an easy task, but in her own case it was not that difficult because her husband is a God fearing man.

*Some people that are detected positive will say haa! I won`t tell my husband, he will kill me. Already you have known the kind of man you have. In my own case it was not like that. He is a principled man, so he is a God fearing man, so immediately he saw it, he said there is nothing too difficult for God (aw0071fn).*

While another who was thrown out by her first husband made sure that she disclosed everything about herself to her new husband prior to their wedding, including her HIV-positive status.

*The man I got married to I let him know everything, every damp thing about my life, because I don't know how to lie. I told him this is what is going on, I have an issue already, am living with this, so how will you feel? He said okay, fine (as0481fn).*

**A nightmare/ Disclosing to a church member:** Of course, the understandings of family members on HIV determine their reactions when it is disclosure to

them; and the reaction may be supportive, hostile, or ambivalent (Kimberly, Serovich, and Greene 1995). In NordPol (2007), respondents find it easier to disclose to friends than parents and other relatives. Similarly, a Finnish participant sees disclosing to her family members as a nightmare due to their limited and erroneous knowledge on the disease. Nevertheless, it has been much easier disclosing to her friends.

*Well, telling my family was a nightmare, it was a lot of crying you know thick emotions and crisis... Is much easier with friends than family members. Everyone know what is flu, what is diabetes, so you take insulin and stuff, but if I say I have HIV is just like when I tell so many I will have to explain so much what`s happening with me and the world, my body, am I dying and what`s the end, it`s just so, well for me I don`t want to do it anymore, is just so if I could tell someone I have HIV okay see you tomorrow. People just have so different ideas so it get really stress and they start crying so you know, so people`s ideas about the disease it could be anything, so is so difficult, just to tell and hope that they know what HIV really is nowadays in Finland, but (sh0485ff).*

But on the other hand, some say 'a problem shared is a problem solve'. So despite the toughness of disclosing positive status the act can somewhat serve as a healing balm. A Nigerian participant summoned the courage and disclose to her church member, and the act apart from giving her relief from suppressing thoughts on her difficult experience (Pennebaker, Colder and Sharp 1990), the member gave her connection to where she received her first free medical treatment.

*Then 2002 it was one man in our church, our guardian in the Lord, we confined in him because he is someone you can rely on, he had to connect me to one nurse that is working at Lagos Island Hospital.... I have come to find out that is very good for you to confined, to disclose to somebody because when you don't disclose it looks you are carrying a heavy load, then when you tell somebody it will be relieved. And each time you are down, that person will be there to help you out. But when you don't tell somebody what is wrong with you even somebody that is sleeping the same house with you, the person might think you are just having ordinary malaria, and will just overlook you, and you will be there dying silently. It is very very good you confine in people that you know will not (aw0071fn).*

**Don't tell at workplace/ Disclosure at workplace:** One`s place of work is often seen as a fortress that should be jealously guided because the loss of self-confidence at workplace or that of job itself affects a lot. So for one Finnish participant it will not even cross her mind to disclose to her colleagues at workplace or even her employer. She may only do so if she is compelled due to some special reasons.

*It won`t even come to my mind to tell my work colleagues ... I [don't] know why they will have to know it, so I don`t think why it will affect my work, I don`t know why I would tell any employer. ... but in years, but I don't know what`s gonna happen, and at that point is depending where am working, I*

*might tell my employer, but not if I don`t have like any special reason to do it (sh0485ff).*

But her Nigerian counterpart who shares an opposing view, believes that, it is wiser to disclose one`s positive status at workplace in order to avoid been hurt by the status leaking through other means.

*I will tell them, because if I don't tell them is going to affect me. The way is going to affect me is that if I want to go and take my drug, there is no way it will not affect. Aside of that I don't need to lie to my boss. If he does not want me fine (as0481fn).*

**Private thing/ Public disclosure:** In societies which have continued to stigmatise HIV as a disease of deviants, hiding one`s positive status has always been a survival strategy (Clarke 2004). So many who do not disclose their positive status believe it does not concern others (NordPol 2007). So a Finnish participant after some number of disclosures (because she had the feeling that hiding her status from people was wrong[32]), has now come to believe that being HIV-positive is only but her private thing (this footnote story among other reasons led to her present stand)[33].

*I have this feeling that if I don`t tell people that I have it do something wrong, that am hiding something they have the right to know, but now I have started to realise that is my private thing you know, I don`t need to tell the world (sn9975ff).*

For another Finnish participant, though her positive status is known by many of her colleagues already, she no longer discloses her status at workplace.

*I no longer tell about this at work, but quite a lot of people know, because during my initial shock- phase I was too open about my condition (ms9367ff).*

But on the contrary, three of the Nigerian participants are publicly disclosing their HIV-positive status. One acknowledged that earlier it was difficult, but now PLWH have started to declare their status publicly.

*Not only in Nigeria around the world, before you declare your status you are strong then. Now, presently, people are trying to (ht0484fn).*

[32] "When I was using drugs, and someone finds out from someone else not me, say hey why didn't you tell me – makes me feel like I did something bad, like I have the responsibility to tell everyone (sn9975ff)"

[33]"There are some people I have met some friend of mine for a long long time ago, it wasn't long ago like maybe 3 weeks ago I met this girl, she was doing [drugs] – I lived with her when I was studying, she was doing this drugs she quitted. She doesn't know about this disease and I met her and we were really good friends long time ago but then we lost contact and now was really happy to see me and you know she was very friendly but then she said this one sentence her man she was dating lived with us then, "he has a lot of women, he likes Russian women" and she said "well maybe he will die of AIDS, that`s not her problem", just that one sentence made her, or I will see the gap between us is really this big, is just you know, I refused telling her about me. That is one thing, people around me, they know that the disease has a face, you know they has my face, it has my face, to them it has made the disease like much less scary in their eyes (sn9975ff)".

Another said many of the PLWHA in Nigeria are now publicly come on air to declare their positive status, and by so doing the understandings on the disease is getting better.

> *People coming out to say they are HIV-positive – declaring their status. That way people know that HIV is actually not a death sentence, I cannot count those who come on air to say their status, and they are doing well – married with kids (tp0389fn).*

Then the third Nigerian who is even more radical about public declaration of positive status sees nothing special in HIV. She said her participation in public declaration is aimed at equipping people with facts about the disease so that they don't kill themselves just for testing HIV-positive. As she narrated it, she has on many occasions publicly declared her positive status in order to give a human face to the disease.

> *What`s in HIV? We have to public, we have to publicise it so that people will know that is not a deadly disease, so that when they come across it they will know that they don't need to kill their selves before the death come…. Is not everywhere, but when people say 'HIV oda oh! Ahh omo ko ni HIV nlewa' (HIV is not good, someone in our neighbourhood has HIV) that I will now come in – "as am here, I am living with it, nothing is wrong with HIV". People might run away, but I will still say my own.... So I met a lot of people, I talk to them about HIV, living with HIV is not the end of the world. I saw boyfriends and girlfriends I talk to them about HIV, 'look at me am living with HIV and healthy'. A lot of them ran away, later on when I was talking they came closer (as0481fn).*

**Drawing people closer/ Keeping hope alive:** Since HIV/AIDS in Finland is still seen in the image of fearful, deadly, and immoral disease, it in return affects personal narratives, lack of which is affecting the acceptance of the disease in the Finnish society. It is unfortunate that only 3/400 Body Positive members are willing to give interview with their names and faces (Clarke 2004). Nevertheless, some of the essence of being open about one`s status have started to emerge. One of the Finnish participants said she has started to acknowledge that whenever she disclose to a person, their relationship is strengthen and the individual will also share something personal with her.

> *Sometimes you know, I think that when someone get close to me, or when I tell someone, it actually, more often it affect our relationship in a good way, it makes it deeper, you know they may be start sharing things about their life, and they consider it an honour that I let them know, that I share it with them (sn9975ff).*

In the light of emerging importance of disclosing positive status, a Nigerian participant advocates that more of the PLWHA should be encouraged to disclose their status in order to keep hope alive and by doing so those who are hiding will be encouraged to come out.

> *More people should be encouraged to come out and disclose their status. When you are coming out to disclose your status will keep hope alive. More*

*people should be encouraged to disclose their status that way you are giving more to those who are hiding (tp0389fn).*

### 4.4.4 Summary on disclosure of positive status

In this sub-category a total of 12 themes (6 each from the Finnish and the Nigerian participants respectively) emerged on the participants` views and experiences with disclosing their positive status. They revealed that though some of the participants selectively disclose their status, the Finnish participants are more conservative about theirs. Amid its difficulties, the Nigerian participants have disclosed to their spouses; based on promising experiences, a Nigerian participant encourages others to disclose even to their church members. Then while it will not cross the mind of a Finnish participant to disclose to her colleagues and employer, a Nigerian participant will prefer to do so lest its leak backfires on her.

For one Finnish participant, disclosing her positive status to family members who often attach emotion to it has been a nightmare, while disclosing to friends is much easier. One of what worries another Finnish participant most is that she repeatedly discloses her status at every time she goes for medical treatment though most of the treatments have nothing to do with HIV. Then unlike before, she no longer feels that her not voluntarily disclosing to people is a wrong act. But a Nigerian participant on the other hand sees public declaration of positive status beneficial in the war against HIV/AIDS stigma and discrimination, and some of them have already publicly declared theirs. Furthermore, while a Finnish participant from personal experience believes that disclosing her status draws people close to her, a Nigerian participant believes that it keeps hope alive and prevents others from hiding their positive status.

For further insight, concept maps in figures 19 and 20 in pages 143 and 144 separately mapped out the overall social health impacts of HIV as experienced by the Finnish and Nigerian participants, and table 20 in appendix IV shows the comparison between the Finnish and Nigerian participants` experiences with disclosing their HIV-positive status, and the comparison was backed with findings from earlier studies. The next sub-category explored the participants` experiences with stigma and discrimination.

### 4.4.5 HIV stigma and discrimination

It is well established that HIV/AIDS is highly discriminated and stigmatised even within the medical Para-status. Many studies have acknowledged the anxiety felt by healthcare workers who come in contact with PLWHA (Hodgson 2006). In this sub-category, the encounters of the Finnish and Nigerian participant with stigma and discrimination have been analysed. Starting with the experiences of the Finnish participants in health centres, the emerging themes are: ‘brutal treatments at health centre, embarrassments at health centre, ill treatments from a dentist, embarrassment at church, rejection by family members, embarrassment from a hair dresser, leaving in bondage, changed attitude, less struggle, and a call to amend and implement HIV laws’. While that of their Ni-

gerian counterparts are: 'lots of discrimination, being rejected by a doctor, no medically related discriminations, public disgrace, embarrassing questions, being stigmatised and discriminated at workplace, isolation, self stigmatisation, declining stigma as in TB, and a call to amend and implement HIV laws'.

**Brutal treatments at health centre/ Being rejected by a doctor:** Narrating her experiences in the hands of medical professionals, a Finnish participant who has lived with the disease for about 20 years said the doctors were initially very brutal on her even to the point that one doctor said 'medical-wise – she has no hope'. Nevertheless, her remaining alive till date has proved the doctor wrong.

*The medical attendants and doctors in the beginning where much more brutal. One doctor once said thait 'medical-wise there is no hope for me'. This has turned out to be a lie (ms9367ff).*

Such discrimination is also in Nigeria where one in ten doctors and nurses admitted haven refused to care for HIV/AIDS positive patients (Ogunjuyigbe, Adeyemi and Obiyan 2009). Narrating her personal experience, one of the Nigerian participants said she was rejected by a doctor in the eastern part of Nigeria just a day to her delivery; as such she took the next available bus back to Lagos where she delivered. Beside the rejection and its emotional stress, this participant was made to undergo about 8 hours all night trip with a 9 months old pregnancy. After a successful delivery her plan of confronting the doctor was aborted by her husband.

*A day to my delivery day, the doctor said to me well madam I cannot handle your case. I was heavy, very heavy. The next, we left immediately and then I went home carried my bag, pick a ticket, and took night bus and returned to Lagos ...when I had that baby, it was very fat and healthy, when I travel I said to my husband I want to go and confront this man, to tell him you see this child, that was the child you rejected because I was positive, and my husband said no (aw0071fn).*

**Embarrassments at health centre/ No medical discrimination:** Hospitals supposed to be safe haven for PLWHA, however, they still receive discrimination there. A Finnish participant recounting how the disease has hunted her said, since the disease appears in all her medical records, health care professionals detested attending to her during delivery. But she feels bad most for their discrimination against her HIV-negative child.

*Like when I was having my daughter, like during labour, of course like it was in all my papers, and I could see it affect some of the health care professionals. And usually I can see them go like – it takes time for them to come back '...hey put gloves on shi shi shi' (during daughter`s treatment), that was really terrible (sn9975ff).*

Sounding different from others, a Nigerian participant said she had never experienced any form of discrimination from health care practitioners.

*They know my status, and they treat me. Different doctors attend to me, they know my status and they treat me. There was a time I had my baby and the*

*placenta took in, they brought the placenta out through what is it called? – Elbow glove (as0481fn).*

This means that, despite its rampancy, it is not all the PLWHA who have been discriminated against by health care professionals.

**Ill treatments from a dentist/ Self stigmatisation:** Another Finnish participant received a big surprise when a small town dentist became confused about how to handle her appointment.

*I think like once in a dentist or something, when I went to this small town dentist, well big surprise, he didn`t really know what was going on and he wanted like, well he didn`t know what to like should he like put my appointment like the last one and what protection to use and what to do he was really out of it, he was kind of wired (sh0485ff).*

But her Nigerian counterpart acknowledged that she is the one who has been stigmatising herself by thinking that she was not going to be able to leave the shores of Nigeria because of her positive status. The self stigmatisation continued until she recently realised that she cannot be denied a visa just because of her positive status.

*I will even say I am the one stigmatising myself, because even before last year I made up my mind to travel, I thought me being HIV-positive, I won`t be able to travel. I might be denied the visa because of my HIV status. I stigmatise myself, nobody stigmatises me because I felt I might not be able to go beyond the shores of Nigeria just because of my status. I don't know if you get it? At a point when I now got to know that oh, that is not even a problem. The only thing that will make anyone give you special attention is if you test positive to 'Yellow Fever' or whatever is called. I don't remember suffering, having any encounter with stigmatisation [afterwards] (tp0389fn).*

Another Nigerian participant who agrees with her said stigmatisation starts with the individual who is HIV-positive. When one starts to avoid people and social gatherings the individual stigmatises himself or herself, and such lifestyle is tantamount to killing one`s self. But if one otherwise attends occasions well dressed, nobody will know that the individual has HIV.

*The stigma and discrimination start with you that is positive, when you discriminate yourself, like now you are tested positive, you start shying away from people, when you don't discriminate yourself, people will not discriminate you, when you are up and doing. Meet with people, if is church, go to church, attend to party, attend to party in a way you look well, but when you discriminating yourself, you stay inside and lock yourself, you are killing yourself. But when you mix with people nobody will know what is wrong with you, and even if you go to occasion you dress better than those who are well (aw0071fn).*

Another Nigerian participant simply said:

*I walk freely as if nothing is wrong with me (as0481fn).*

**Embarrassment at church/ Lots of discrimination:** In Christian religious cycle where in accordance with Christ`s example, 'discrimination' is preached against, a Finnish participant claimed that she was twice embarrassed. The first embarrassment came from a mentor who said **'**HIV is God's punishment, and a form of it is being spread through sneezing'. The second embarrassment came from a pastor who before her new male friend pointed a finger at her and said, 'those who are sick should not infect others'.

*Once a christian mentor I had told me that hiv is God's punishment and the bowl of wrath from the book of revelations. She also told me that there was a form of hiv that has crossed itself with ebola and it spreads by sneezing. ... A pastor at my church pointed a finger at me from the pulpit. I had brought a male friend of mine to the congregation. The pastor proclaimed that 'those who are sick should not infect others' (ms9367ff).*

Just as social inclusion contributes to lowering HIV/AIDS discrimination (Clarke 2004), social exclusion worsens it, which is why in describing what HIV/AIDS discrimination looks like in Nigeria, a Nigerian participant likened it to being made an outcast.

*They discriminate a lot, people look at it as the worst disease that, like if you have committed, like maybe in the olden days they say when you commit any crime, they will throw you into the evil forest that is how they are still looking at it. Even some of them if they know that you have it, they will disassociate their selves from you, but the enlightened ones don`t (aw0071fn).*

Another Nigerian participant simply said:

*A lot! (as0481fn)*

**Rejection from family members/ Public disgrace:** In accordance with Honarvar (2010) which argues that, disclosure of positive status to family members may lead to behavioural change, a Finnish participant said her family members instead of supporting her, they rejected her after she disclosed her positive status to them, and as well did all kinds of thing to dehumanise her, even to the point of labelling her a tramp, unlike her good friends.

*Some people startted acting funny, including my mom, who disinfected surfaces I had used or touched, peole feared using the cups, cutlery or toilet I had used. Some did noy want to have anything to do with me. Some judged a lot almost labeling me a tramp…. My mother refuses to get correct information. The only instruction she knows are fron 1980's, my sister, who is a nurse gave them to her. This means disinfecting after me and washing my clothes in a very high temperature separate from others. She doesn't let me do normal functions like drive a moto or a car, like I was handicapped ... My family it a bit strange towards me, always wery wary. But the good friends I have don't care (ms9367ff).*

Then notwithstanding that family members` support and comfort contributes to relieving the impacts of HIV/AIDS (Aga, Kylmä and Nikkonen 2009), a Nigerian participant instead suffered public disgrace through her former husband.

Tearfully she said he use to go about telling people that his wife is HIV-positive, but since there was no sign of such in her body, she claimed otherwise.

*My first husband did that, he use to tell people – 'she is living with HIV' this that blaa, blaa, blaa, that never shake me because I look at my front God you are the one am seeing, I look at my back, I see God everywhere around me, so why should I be afraid of human being. If he says anything about me, I will tell those people do I look like someone who has HIV? (as0481fn)*

**Embarrassment from a hairdresser/ Embarrassing questions:** A Finnish participant said she was surprised when a hairdresser who had been her very good friend suddenly began to use glove while doing her hair, and that led to her asking the hairdresser a question that made her feel embarrassed.

*A wery good friend of mine is a hairdresser. I wondered when she started to dress my hair with cloves on. I asked if she was allergic? She was embarassed, then I realizede why she had done it. She has not done it since (ms9367ff).*

Furthermore, in Cao et al. (2006) study of 601 female migrants in Shanghai, 54.6% of the respondents believe that those who acquired HIV through sex and drug abuse deserve it, but the million dollar question is – how do we know those who contracted the disease through sex and drug abuse? It is unfortunate that one the greatest challenge faced by PLWHA is that they are classed by many as flirts and immoral individuals who have gotten what they deserve. As narrated by two of the Nigerian participants, some people go as far as confronting them with embarrassing questions. One said people confront her with many question which includes – are you a flirt? But instead of being provoked, she had always replied that she is not, instead remained a virgin until she got married.

*I have a lot of friend that will say (name withheld) are you, how did you come across it? They ask me a lot of question – are you flirting around? Are you this are you that? I told them no! Am not flirting around, I never flirt around, I was a virgin when my husband got married to me (as0481fn).*

Then the other is often confronted by those who say to her – they heard that she has AIDS! But in her defence she had always told them that what she has is HIV and not AIDS. She also uses the opportunities to educate the individuals about the disease.

*Some people you know don't come to you, some will meet me on the road and said (name withheld) they said you have AIDS. I will tell them no, "I don't have AIDS, I have HIV". For me is an opportunity to educate that person, so it gives me an opportunity to educate (ht0484fn).*

**Living in bondage/ Isolation:** Unlike the participant in Anderson and Spencer (2002, 1347) who says "*...I don't let this put me in a box....",* a Finnish participant feels she is living in bondage by not acting freely and allowing people to come close to her just because she wants to keep her status away from people.

*It`s in a way like I don`t behave or act as freely as I would like because am afraid to let people know who I am, I don`t want them to get too close they*

*will find out this terrible secret to me because, I don't want them to, they will find out (sn9975ff).*

Similarly her Nigerian counterpart acknowledged that isolation is one of the bitter pills PLWHA must swallow. She believes that the best remedy for such is that they do not isolate themselves too. Although people call her names including labelling a prostitute, she is not moved.

*Normally you are expected to come across such. They will try to isolate one, but is you that will not isolate yourself – I know that nothing is wrong with me. They will call you asawo (prostitute), they will call you a lots of name, but so far you know that you don't do it, why will you be afraid of? (as0481fn)*

**Changed attitude/ Being stigmatised and discriminated at workplace:** Unlike an interviewee in Clarke (2004) who was refused a job by an occupational health doctor simply because he has HIV, one of the Finnish participants whose positive status was not a barrier to her being hired, (probably because it was not disclosed to her boss) said recently the attitude of her boss has changed, however, she is not sure if her boss has been informed about it. But besides this recent suspicion, what she had constantly struggles with is people`s attitude towards her. At first, she use to cries about it, but now it moves her no more. She also believes that slowly people`s attitude towards her is getting better even to the point that her church which once rejected her, has reaccepted her.

*My bosses attitude changed along the way. I don't know whether she found out.... Just having top deal with attitudes, at first I got hurt and went home to cry. Lately I have been like: So WHAT!. The attitudes are slowly starting too change. At my church I was finally accepted... I feel like God has finally started to pay me back all the years the locusts ate (ms9367ff).*

As Clarke (2004) also acknowledged, PLWHA may face social exclusion which include job and housing discrimination; a Nigerian participant argues that though medical discriminations are going down, it remains high at workplaces where people are still being sacked because of their HIV-positive status.

*Stigma has been high, discrimination especially in the workplace, but I feel secured. Stigma is still there but it has been reduced, and we can do better.... For me it has reduced especially in health setting, but we can do more in the workplace. At the workplace we still have organisation still sacking people because of their HIV status (ht0484fn).*

**Less struggle/ Declining stigma as in TB:** The Finnish participant who was embarrassed by a dentist claims she is lucky in the sense that unlike many others her friends still relate well, as such she does not have much trouble coping with the disease.

*I don`t think I see myself very differently, am lucky in a way that when I found out I told all my friends, and no one has treated me any different, so I really haven`t had to struggle with that so much [like many others] (sh0485ff).*

Then a Nigerian participant expressed her believe that, HIV/AIDS stigma will someday decline insignificantly (like that of tuberculosis and missiles), and there are already signs.

*I think tuberculosis, I remember one of my relation has tuberculosis, every person use to run away, you understand, you know is a very deadly disease, even missiles you know, since those ones can go down, HIV will still go the same way. The thing is reducing unlike before (aw0071fn).*

**A call for the amendment of HIV laws/ A call for the implementation of HIV laws:** All the three Finnish participants extensively advocate for HIV laws to be amended in their favour – especially the laws which permanently tag them 'criminals' and others 'victims', while the Nigerian advocate for its implementation. Although they do not have full understanding of HIV/AIDS laws, but based on what they have witnessed so far, the Finns believe that much need to be done as tactfully and comprehensively expressed below:

*Now if someone has sex with a hiv positive person, that other one can practically start accusing the positive one of a crime. Sex is always a deal of two. Both sides should take the responsability. Take for example the case of that african prostitute. She was selling sex, the men bought it knowing she was a pro. Yet they did not use a condom. When they learned she was posituve, they sewed her. Weere they not responsable for their actions Who does it with a pro unprotected? Even though no- one was infected and she claimed to have used female condom, she was sentenced to prison, her photo and name published in a newspaper. Witchhunt eh?*

*Those guys who bought sex, which in fact in opressing and abusing of a woman were so called" victims". This law should be changed (ms9367ff).*

*Well, I haven`t really, am not quite sure like how the law different between different countries, but in Finland I will like the law to be more clear, like because is kind of like grey area if you infect someone, and someone prosecute like what is happening, so is kind of, there should be like basic rule like some protection for HIV-positive people like, am not sure how in Finland it goes what actually happens if someone. Yeah, I think like more especially like HIV-positive people should have more protection law wise….. I think that is really difficult. Okay like if you don`t use condom, I don`t is just weird that it can be said that the saying like you attempt to like murder someone, so in the laws well I thinks that`s a bit, oh yeah, you are not with a gun somewhere, so I think like it be a bit more easier, especially if you haven`t really meant to do any harm, okay, if you actually wanted to infect many people then is bad, and like it varied like in Finland, Sweden, Norway, Denmark, I don`t know how the law works, but I have heard that like even though we are close, the laws is kind of different in every country like some country is better some worse, there should be like more like worldwide consensus unlike what is happening* (sh0485ff).

*Well, I know this, this law that somehow criminalises, emm criminalises if you, if someone else, if you like infect someone else with this disease. I don't, maybe I, I think maybe should be changed. I don't know if is practice still,*

*but I know this really this friend of my she died of drugs she was young girl, woman she died few years ago but she was very very young when she got this disease, she was using drugs and she had really hard life, and I think she was maybe 19 years old at the time, and she went to this bar and this probably 30, 40 years old man who work at the bar probably seduced her and took her home and went to bed with her and then afterwards he found out that she is HIV-positive, he sued her for not tell him, and she got a fine she had to pay and in that really that case because I know my friend I know the story emm I really think she was the victim, because she was seduced, so. (Was the man infected by your friend?) No, yet he still sued her, and it was in all the papers and you know, and you know. I don't remember if her name was there (on the papers), but at list all the people work there, or live there in that area am not sure they didn't know it was her. He probably found out from someone who knew her, yeah. Emm, I don't know how it is, but I think you know because the law should also protect the people (PLWHA), emm you know in case I if I would start seeing someone and then afterwards, but I don't think you should, it should be a crime if the other people doesn't get this disease, it should you know that should be criminalised not telling. Of course you have, I have moral obligation I think to tell about it, but I don't think it should be in the law that I have to tell people (before you have sex with them?) yeah, yeah. Or if, well that is maybe not, am not quite sure my stand at that, at that, on that issue, but at least there should be some way of protecting you know that someone who who is mad at me, although he knew he would say 'she never told me'. I don't know, maybe that, maybe, maybe that criminalisation of this, this disease should be changed* (sn9975ff).

Then two of their Nigerian counterparts also registered their concerns. While one is concerned about legalisation an implementation of laws HIV/AIDS laws in Nigeria.

*...to legalise laws; a lot of laws in Nigeria but is not being implemented. There is a law in the house of assemble, it has not been legalised. We need it to be legalised (ht0484fn).*

The other prefers to see among other improvements changes in the attitude of the Nigerian Police towards PLWHA.

*To have the right, equal right to, but I think the law should actually look at our police officers, in the sense that our police officers should be consecrated (corruption free). The law should back us up in the sense that if you come to stage report, do not talk down on us, do not make jest of us you know is all about the government should improve in education our population (tp0389fn).*

### 4.4.6 Summary of HIV stigma and discrimination

In this sub-category a total of 20 themes (10 each from the Finnish and the Nigerian participants respectively) emerged showing the participants` experiences with stigma and discrimination. There was almost one-on-one correspondence

between the Finnish and Nigerian participants` themes, and they reveal that living with HIV/AIDS increases one`s chances of being discriminated and stigmatised. Going by a Nigerian participant`s point of view it, PLWHA are termed – 'outcasts'. Being a problem that has no boundary, HIV/AIDS discrimination has found its way into health care centres which supposed to be the safe haven for PLWHA. All the three Finnish participants in one way or another have been discriminated against by health care professionals, and a Nigerian participant who had similar experience said she was made to go on about 8 hours trip back to Lagos just hours before her delivery because a doctor refused to attend to her delivery. But contrary to that one of the Nigerian participants said she has had no discrimination from health care practitioners.

Besides receiving embarrassments from medical practitioners, embarrassments came from other sources. One of the Finnish participants received embarrassment from a hairdresser who suddenly choose to wear gloves while doing her hair, and late from her church where her mentor said HIV is God`s punishment, and subsequently a pastor pointing at her in the presence of her new male friend said "those who are sick should not infect others". As if that was not enough, her family members repeatedly rejected and dehumanised her. A Nigerian participant who had similar fate got public disgrace through her first husband who was going about telling people that his wife is HIV-positive. Then a Finnish participant considering what the disease had reduced her to said she is now living in bondage by not relating freely with people lest they find out that she has HIV. As believed many, PLWHA are at the danger of being seen as flirts and drug addicts which is the reason why one Nigerian participant was confronted with the question – did you get the disease through flirting? But since she was a virgin before getting married, she had always used that honour in her defence. Another Nigerian participant who is often confronted by those who say they heard she has AIDS has always replied them that what she has is HIV and not AIDS.

A Finnish participant said that though she does not know why the attitude of her present boss has recently changed, she had always dealt with people`s attitude which is by the way getting better. For instance her church that once rejected her has now reaccepted her. A Nigerian participant still thinks that workplace discrimination remains high in Nigeria and that is responsible for the loss of jobs experienced by many of the PLWHA. Another acknowledges that though isolation that includes being labelled a prostitute is part of the cross they must bear, the only way to lighten the burden is by not isolating themselves. Yet another said she has been the one stigmatising herself by thinking that she will be refused a visa to travel abroad. Another Nigerian advised that PLWHA should not avoid social gatherings; instead they should attend fabulously dressed. She also believes that HIV/AIDS high stigma will someday become a thing of the past as in as in TB (tuberculosis). Finally, participants from both countries advocate that HIV/AIDS laws should be amended in their favour. This sub-category also reveals that there is no much difference in the experiences of both group, and that some of the agonies suffered by PLWHA due to HIV/AIDS discrimination and stigmatisation may be difficult to describe with words.

For further insight, concept maps in figures 19 and 20 in pages 143 and 144 separately mapped out the overall social health impacts of HIV as experienced by the Finnish and Nigerian participants, and table 21 in appendix IV shows the comparison between the Finnish and Nigerian participants` experiences with stigmatisation and discrimination due to their HIV-positive status, and the comparison was backed with findings from earlier studies. The next sub-category explored the impacts of HIV on participants` relationships.

### 4.4.7 HIV impacts on relationships

In Cao et al. (2006) study of the reasons, sources, and types of HIV–related stigma prevalent in rural China, behaviours were primarily associated with fear of the disease rather than the route of it. Such fear sometimes pitches its influence on social relationships. In this sub-category, the aspects of the participants` experiences which are associated to social relationships have been explored. The themes under which the experiences of the Finnish participants were described are: 'keeping safe distance from men, harder task in finding a partner, there is still a chance to fall in love, and steady relationship, escape-goat'. While that of the Nigerian participants are: 'meeting people, an opportunity to find a life partner, not a barrier to marriage, love without measure, starting a more permanent relationship, knowing true friends, a test of family love, and strengthening of family'.

**Keeping safe distance from men/ Meeting people:** As a 36 year old Finnish participant puts it – living with HIV scares her away from men, and that has been limiting her chances of finding a life partner at her prime. That is; her HIV-positive status forces her not to allow her relationships with men to go beyond friendship at a time when she should. However, to her it seems things are changing.

> *Emmm maybe it does affect my social life in a way that maybe am scared of you know not looking for a partner, like getting to know men, you know it`s, I like to keep men like a safe distance maybe as friends you know. Maybe that is all changing as well (sn9975ff).*

Another who is still single at 43 simply said:

> *I miss a relationship with the opposite sex (ms9367ff).*

But on the other hand, a Nigerian participant sees it as an opportunity to meet new individuals – especially amongst the PLWHA. Then besides the courage she got from meeting people whose conditions seem worse than hers, living with the disease enabled her to attend beneficial seminars and workshops.

> *I met people, I met a lot of people, people who even have worse effect than I did when I got to know my status, you know that gave me the courage to move on.... I attended seminars, workshops to learn. It`s very good for me, is very good for me, it helped me to know more people (tp0389fn).*

Another who also had the opportunity to meet other PLWHA said, it take away her fears of being a lonely HIV sufferer.

*And when I got there I saw people older than me and people younger than me and my mind told me 'you are not alone' (ht0484fn).*

**Harder task in finding a partner/ An opportunity to find a life partner:** It seems finding a partner is becoming tougher nowadays, and HIV/AIDS being a self-limiting disease may make matter worse (NordPol 2007). Accordingly, a Finnish participant said sometimes she feels that being HIV-positive has made it much more difficult for her to find a man to share her life with.

*Sometimes I feel that it will make it harder for me to find someone like a man to share (sn9975ff).*

But contrary to this, three of the four Nigerian participants believe that living with HIV has actually increased their chances of finding life partners. One of them who is a Muslim said, she had in mind finding a life partner among the PLWHA, but what stopped her is that she did not find a very committed Muslim among them so she sought for one elsewhere.

*I never see, that was in my mind. If I see a Muslim, if I see a conk Muslim, if I see a strong Muslim that I want among those living with HIV. I prefer a strong Muslim to someone living with HIV (as0481fn).*

Another who was already marry before she tested positive to HIV said, at their support group meeting, people have always tabled their needs among which is – 'I need a life partner', and that has been an effective tool.

*That support group is where you come, you speak your mind, even those that are looking for husband will come and say there – I want husband oh, I want to marry oh, so they know how they can find somebody or connect you with somebody (aw0071fn).*

Then the third one said she still has her old friends, and living with HIV added new ones.

*I still have my friends, and added as well (tp0389fn).*

**There is still a chance to fall in love/ Not a barrier to marriage:** In line with a recent trial which shows that antiretroviral therapy can reduce the chance of one infecting his/her HIV-negative partner by up to 96% (WHO 2011), one of the Finnish participants said she now sees herself less infectious because her medications have to a large extent reduced the level of the virus in her, so if she falls in love with a man now, she might not infect him.

*Now that I know that because of the medication, I know that am not you know dangerous, you know if I fall in love, find like a man you know, I know that you know he can`t get the disease from me that easily because I have here, the virus is so low and everything (sn9975ff).*

Strengthening this view, a Nigerian participant said that HIV-negative individuals are now marrying HIV-positive ones, and they are living happily giving and birth to HIV-negative children.

*People are marrying positive, negative people are marrying positive people, positive people are marrying positive, and they are having negative children, and they live happily (aw0071fn).*

**Steady relationship/ Love without measure:** A Finnish participant said she had lived with her HIV-negative boyfriend for 5 years, and because she would not want to put herself under the stress of finding another partner like many others in Finland, she plans to spend the rest of her life with him. A decision which seems uncommon in a society where about half of the marriages end in divorce.

*At the moment am living with a man, we`ve been together for about 5 years. It was lucky for me in a way that he was a friend before, also before I got HIV, and when I found out I told him, and he was still my friend then and took it like everybody else, and then he made the first step, and asked me out so it hasn`t been a problem with him, but I don`t know how it could have worked if I was just like meet someone who would have been interested and then told him.... he knew and then he still decided to have relationship with me, so I have been pretty lucky because I also know some people that don`t want to meet anyone because they don`t want to explain and go through all that, I don`t really have to go all through it, and it looks like am going to be with that guy hopefully for the rest of my life, so I don`t have to put myself in that situation so I don`t know (sh0485ff).*

Then from the perspective of two Nigerian participants, living with the disease has given them reasons to love their HIV-negative spouses much more. One of them who got remarried 5 years after her first husband left her said she loves her new HIV-negative husband more than anyone else including her own father, and will always do so because her being HIV-positive did not discourage him, but instead he took her for whom she is, and as a result he does not use the disease to abuse her like her former husband.

*But ever since then I have moved on with my life, and after some years I got married again – after 5 years. It never affect my relationship because I let him understand that…, he does not isolate me. I love him more, more, more, I love him so much, I love him more than my father. He took me for who I am, and for that reason he has not used it to abuse me like my former husband that when we fight he will tell the whole people in the house (neighbours) – do you know what is in this woman? He is not that kind of man, he is a man of my own, my choice, God has give me, and God will not take him away from me, so I will always love him (as0481fn).*

The other said living with HIV made her see the marriage vows – 'for better or for worse' in action. According to this participant her husband has always been there for her because of the love they both share. So she encourages other Nigerians ladies to marry for love instead of the growing trend of marrying for wealth.

*My husband was carrying me about then, I cannot even, am telling you honestly, that is where you`ll see this vow of marriage working, for better for*

*worse, so I he was always with me. You know already the love was there even before we got married. I married him out of nothing, not because of wealth, just because of that is the way it work, so that is why I always tell people before you get married, don't marry because of material thing, marry because of the love you have for that person (aw0071fn).*

**A scapegoat/ Starting a more permanent relationship:** A Finnish participant said she sees herself as a scapegoat. Contextually, the first used of the word in the Bible (Leviticus 16:10) seems to mean – 'being made to bear the blame of others, or suffer in their stead'. But in expanding what she mean by that she said; 'whenever she meets a guy, she will quickly begin to nurse the feeling that he does not really like her and that pushes her farer away from men'. So though her explanation makes sense, I did not see strong congruence between that and scapegoat.

*A scapegoat – like if I will meet a guy, and I will think that well he doesn't really like me, and also I have this disease, of course he doesn't like me you know (the idea pushes you farer away?) yes! (sn9975ff).*

Another who nurses similar feeling said, she no longer feels that she is attractive enough to find a partner, nor finds it easy to tell a man she has feelings for about her status.

*I no longer find myself attracting, I am not in a relationship. I find it a high treshold to tell anybody about my disease relationshipwise (ms9367ff).*

Then, for two of the Nigerian participants, living with HIV mean sitting up and starting more permanent relationship. One said after testing positive, she immediately ended the relationship she was into, and later started another one with a HIV-negative man whom she is now married to, and the marriage has produced two HIV-negative children. She credits her steady relationship to her husband being a born again Christian.

*When I knew my status I ended the relationship I was in, so for me it was not an issue, so right now am married to someone who is not HIV infected, and also I have two children who are not HIV infected. And it does not affect my relationship ...my husband is a true born again person (ht0484fn).*

Then the other said, she withdrew from having relationship after she tested positive, but now she is in a relationship with a HIV-negative gentleman.

*I withdrew from having relationship, but am in relationship now, and he is negative (tp0389fn).*

**Knowing true friends:** To one of the Nigerian participants, testing positive to HIV gave her the opportunity to know who her true friends are. According to this participant, during the time she was so sick, her friends especially the graduated ones put in their resources to make sure that she did not die, and as a result she became convinced that they are her true friends.

*Some of them that have graduated were up and doing – their friend must not die. Some of them that have started working – I have friends I can call friends. We were really getting along (ht0484fn).*

**A test of family love:** Family household is often the first social safety net in a society, and demonstrates remarkable strong resilience in time of trouble, yet for PLWHA, additional support seems unavoidable (WHO 2002). In Nigeria where the income per capital of many is very low, the living condition of many is pitiful. But despite this odd, a sister of one of the Nigerian participant still accommodated her in a small apartment where her husband and three of their children also live notwithstanding that besides HIV this participant had tuberculosis which is very infectious.

*Even then I was staying with my sister that was married with children – three children. And I have to you can imagine the husband was there, she was there, I was there, they did not say go to your house when your TB is cured you can now come back (ht0484fn).*

Another Nigerian participant said, her immediate family gives her encouragement and love that has been keeping her going.

*The encouragement and love they (family members) give me that is what keeps me going, because when they don't give you that love is another problem (aw0071fn).*

**Strengthening of family:** Unlike in the Finnish welfare state, in Nigeria where social welfare barely exists, family is the only sure economic backbone where many can fall back to in the time of trouble. This is because the relationship within a family is strong and culturally protected. As such, unlike the places where individuals commit suicide due to loneliness and other HIV/AIDS related pressures, a Nigerian participant said her family members made life worth living despite the fact that her family is a polygamous one.

*Life was worth living because of my family, because they were by me, we were together despite the fact that my father had another wife. But none of them run away, in short they were there (ht0484fn).*

Another Nigerian participant who believes that her condition has strengthened her family relationship said, the concern her husband has been showering to her proves that he does not want to lose her to HIV.

*I don't feel lonely at all. People around me are always there for me. It strengthened the love, it strengthened it. Because he is always, even when am out, when it is time for my drug, he always call me, have you taken your drug? That is, he cares you know, he wants me to stay alive (aw0071fn).*

The care and support demonstrated here seems to be in agreement with the counsel of many experts that care and support should neither be too much or too little, because while 'too much' may be overprotective and as such remove the person`s dignity, sense of independence, and self-respect, 'too little' may pro-

vide less of the needed support to ensure the person eats well and has the strength to resist infection (FAO 2002).

### 4.4.8 Summary of HIV impacts on relationships

In this sub-category a total of 13 themes (5 and 8 from the Finnish and the Nigerian participants respectively) emerged revealing the impacts HIV has had on the participants` relationships. There are strong one-on-one correspondence between each of the Finnish group`s themes and 5 of the Nigerian group themes, while the other 3 completely differed. The responses demonstrate that the Nigerian participants were much more positive about their conditions as a result of their many positive experiences. For instance while a Finnish participant will prefer to keep a safe distance from men because she has HIV, two Nigerian participants see it as an opportunity to meet more people. Again while a Finnish participant feels that being HIV-positive has made it much more difficult for her to find a man to share her life with, three of the Nigerian participants see it as an opportunity to find a partner especially within the community of PLWHA.

Furthermore, two of the Finnish participants are saddened by how HIV has twisted their lives. While one sees herself as a scapegoat because she nurses the feeling that men will not like her which pushes her farer away from them, another thinks that she is now unattractive for a relationship with a man because the disease has disfigured her body. Nevertheless, the other Finnish participant believes that she still has the chance of falling in love because her medications has significantly reduced the quantity of HIV virus in her, even to the point that she may hardly infect a man. A Nigerian participant who agrees with her said the disease is now much less a barrier because HIV-negative individuals in Nigerian are marrying HIV-positive partners and they are living happily and reproducing HIV-negative children.

Then though she lives in a society where relationship between couples rarely last, a Finnish participant has lived with a boyfriend for about 5 years, and in order not to put herself into the stress of searching for another partner, she plans to spend the rest of her life with him. Two of the Nigerian participants agree with her. One says because her new HIV-negative husband has taken her for whom she is, she loves him more than anyone else. The other said her condition gave her the opportunity to see the marriage vow – 'for better or for worse' at work in her marriage. For two other Nigerian participants, living with HIV means sitting up and starting more permanent relationships.

Then to a Nigerian participant, testing positive to HIV gave her the opportunity to know who her true friends are. Furthermore, despite all odds, her sister accommodated her in their small apartment where her husband and three of their children also live notwithstanding she also had tuberculosis, which is very infectious. Finally a Nigerian participant said that her family members made life worth living despite the fact that the family she came from is a polygamous one.

For further insight, concept maps in figures 19 and 20 in pages 143 and 144 separately mapped out the overall social health impacts of HIV as experienced by the Finnish and Nigerian participants, and table 22 in appendix IV shows the

comparison between the Finnish and Nigerian participants` conceptions on the impacts of HIV on relationships, and the comparison was backed with findings of earlier studies. The next sub-category explored the impacts of HIV on participants` faith and spirituality.

### 4.4.9 HIV Impacts on faith and spirituality

This is the last sub-category under the social impacts of living with HIV, and it is focused on the impacts of the disease on faith and spirituality. Of course, once someone tests positive to HIV/AIDS, the individual`s life changes automatically, for instance in Anderson and Spencer (2002, 1348) one participant who believes that there are positive things about living with AIDS said: *"If I didn't have AIDS, I'd probably still be out there drinking, drugging, and hurting people. I turned my life around. I gave myself over to the Lord and Jesus Christ."* Similarly, due to loss of self-esteem and other reasons, some non-religious individuals after testing positive to HIV/AIDS begin to search for spiritual help, while some of the already religious ones become more committed to their faith, either because they want the intervention of a higher power or because they are looking for consolation.

Then though in the circularised western societies, seeking for spiritual help makes only but a little sense, in religious Nigerian and other African societies reverse is the case. So this sub-category compares the religious experiences of the Finnish and Nigeria participants after testing positive to HIV. While the three Finnish participants claim that they are Christians, only one seems committed. In fact, the other two admitted that they are not religious. On the other hand, all the four Nigerian participants claimed to be very religious. While one is a Muslim, the other three are Christians. The themes under which the experiences of the Finnish participants were described are: 'drawn closer to God, faith and hope in God, there is a reason for testing positive, and troubles turned around'. While that of the Nigerian participants are: 'going close to God, believe you will make it, relying on God, and God`s grace'.

**Drawn closer to God/ Going close to God:** In accordance with Fryback and Reinert (1999) study of HIV/AIDS and cancer patients which reveals that spirituality is influential to patients` capacity of coping with the diseases, a Finnish participant demonstrated the believe that being HIV-positive has drawn her closer to God, and having faith in Jesus has brought her comfort. As such, she is thankful to God for her life and that of her daughter.

> *I have been drawn closer to God. Spiritually I find a lot of comfort in my faith in Jesus, who is the healer and comforter of those who suffer in our time still. All this has drawn me closer to Him and I thank Him and our Heavenly Father for my life, for my daughters life (ms9367ff).*

Three of the Nigerian participants agree with her. The Muslim among them said:

> *When am down, once I carry my Quran I will be fine. So far I just perform my 'Ablution' and I go close to my God I will be fine (as0481fn).*

Another who believes that God used HIV to draw her close to Himself said:

*...after HIV, I would say He drew me closer, he drew me closer (tp0389fn).*

Then the third who's coping with HIV is fostered by scriptures and Christian music said:

*Being positive has made me more closer to God, now am more closer to God, ...Is God`s word. I put on the music, Christian song (aw0071fn).*

**Faith and hope in God/ Believe you will make it:** Again the same Finnish participant expressed her believe in prayers, especially the intercessory ones. She claimed that she has strong faith in the prayers of her Christian friends, and hopes that Jesus will heal her someday; she further said nevertheless, even if she is not healed, she will continue to serve Him. Then though she feels that her future will be lonely, she still chooses to have faith and hope in God.

*I have some good christian friends who pray for me ... I also believe Jesus can and will heal me. And even if he does not, I will always serve Him. The destiny of my family is in Him. I see my future rather lonely. But I don't know what plans God has for me. I have hope, I have faith (ms9367ff).*

Then a Nigerian participant who expressed similar strong faith said:

*If you believe you can make it, you will make it. If you have that courage in you that nothing is going to happen, nothing will happen.... You will live on if you have that believe (as0481fn).*

**There is a reason for testing positive/ Relying on God:** A Finnish participant who admitted that she is not religious though she is a Christian said she believes that there is a reason why she got HIV. In her view, it is because God deems her strong enough to withstand the disease and its effects.

*I have thought that well maybe there is a reason why I got it, maybe you know God look that she is strong enough to carry it (sn9975ff).*

Her Nigerian counterpart who believes that her good relationship with God is responsible for her being positive minded despite her condition said, if she had believed that her life has come to an end, her lifestyle would have been shaped that way, but because she had placed her life in the hands of God, she is not worried about anything.

*My relationship with God has changed in a way that it has helped me to stay positive too in a way, to stay strong rather because I believe within me – the Bible says, "as a man think so is he". If I have a notion in me that 'this is it', then I will be living towards that kind of life, but the word of God says "we have power that is not our own", that is why on a daily bases I speak to myself; 'this disease you will not take my life' you know, so that in a way has kept me going strong. But at the same time I have placed my life in God`s hand, I know I don't have to worry about anything. When you put God first in everything, and you have peace of mind, like when I tested positive to HIV (tp0389fn).*

**Troubles turned around/ God`s Grace:** Similar to about one-third of the 450 HIV/AIDS patients studied by Szaflarski et al. (2006) who felt that their life after diagnosis is better than it was before being diagnosed with HIV/AIDS, the same Finnish participant who had lived with the disease for about 20 years believes that, her faith and joy in God is responsible for the positive changes in her life, and the troubles worthwhile.

*Faith and joy in Him have turned around all the trouble and made it worthwhile (ms9367ff).*

Similarly, two of the Nigerian participants expressed their dependence on God`s grace. One said she use to be troubled by her condition, but through God`s grace she has been coping well.

*The thing was really disturbing me, really disturbing me, but I keep on trying with God by my side (aw0071fn).*

Then the other said, she believes that her life is sustained only by the grace of God because some of those who tested positive about the same time she did are no more.

*For me God has been wonderful in my life, let me use that word. I remember some of us that started together, some of them are late (ht0484fn).*

### 4.4.10 Summary of HIV impacts on faith and spirituality

In this sub-category a total of 8 themes (4 each from the Finnish and the Nigerian participants respectively) emerged expressing the impact of HIV on participants` spirituality and faith. Each of the Finnish group`s theme seems similar to that of the Nigerians`. The responses therein reveal that though Finland and Nigerian are popular Christian religion countries, nevertheless, the religiosity of the Nigerian participants is greater than that of their Finnish counterparts. For instance, only one of the three Finnish participants said she is religious though the three claimed to be Christians. While as the four Nigerian participants seem committed to their religions. One is a Muslim and the other three are Christians. While the committed Christian among the Finnish participant claims the disease has drawn her closer to God and brought her comfort, three of the Nigerian participants claim the same. The Finnish participant also claimed that her faith and joy in God is responsible for the positive changes in her life, making her troubles worthwhile. She also expressed her believe in prayer, especially the intercessory one. She also has the hope that Jesus will heal her someday; nevertheless, she plans to continue to serve God even if she is not healed. Then though she feels that her future will be lonely, her faith and hope in God are still alive.

Then a Nigerian participant who believes that her good relationship with God is responsible for her being positive minded said, if she had believe that her life has come to an end, her lifestyle would have been bent that way, but because she had placed her life in the hand of God, she is not worried about anything. Furthermore, two of the Nigerian participants expressed their dependence

on God`s grace. While one said she use to be troubled by her condition, but through God`s grace she has been coping well. The other believes that her life has been sustained only by the grace of God because some of those who tested positive about the same time she did are no more. Even one of the Finnish participants who said she is not a practicing Christian said, believes that God allowed her to get infected with the disease because He knows she can withstand it.

For further insight, concept maps in figures 19 and 20 below separately mapped out the overall social health impacts of HIV as experienced by the Finnish and Nigerian participants, and table 23 in appendix IV shows the comparison between the Finnish and Nigerian participants` conceptions on the impacts of HIV on faith and spirituality, and the comparison was backed with findings from earlier studies. This is the end of category four on the social health impacts of HIV (consisting of 5 sub-categories and 64 themes – 31 and 34 on the Finnish and the Nigerian participants` conceptions), The next category explored the positive and negative impacts of HIV on education.

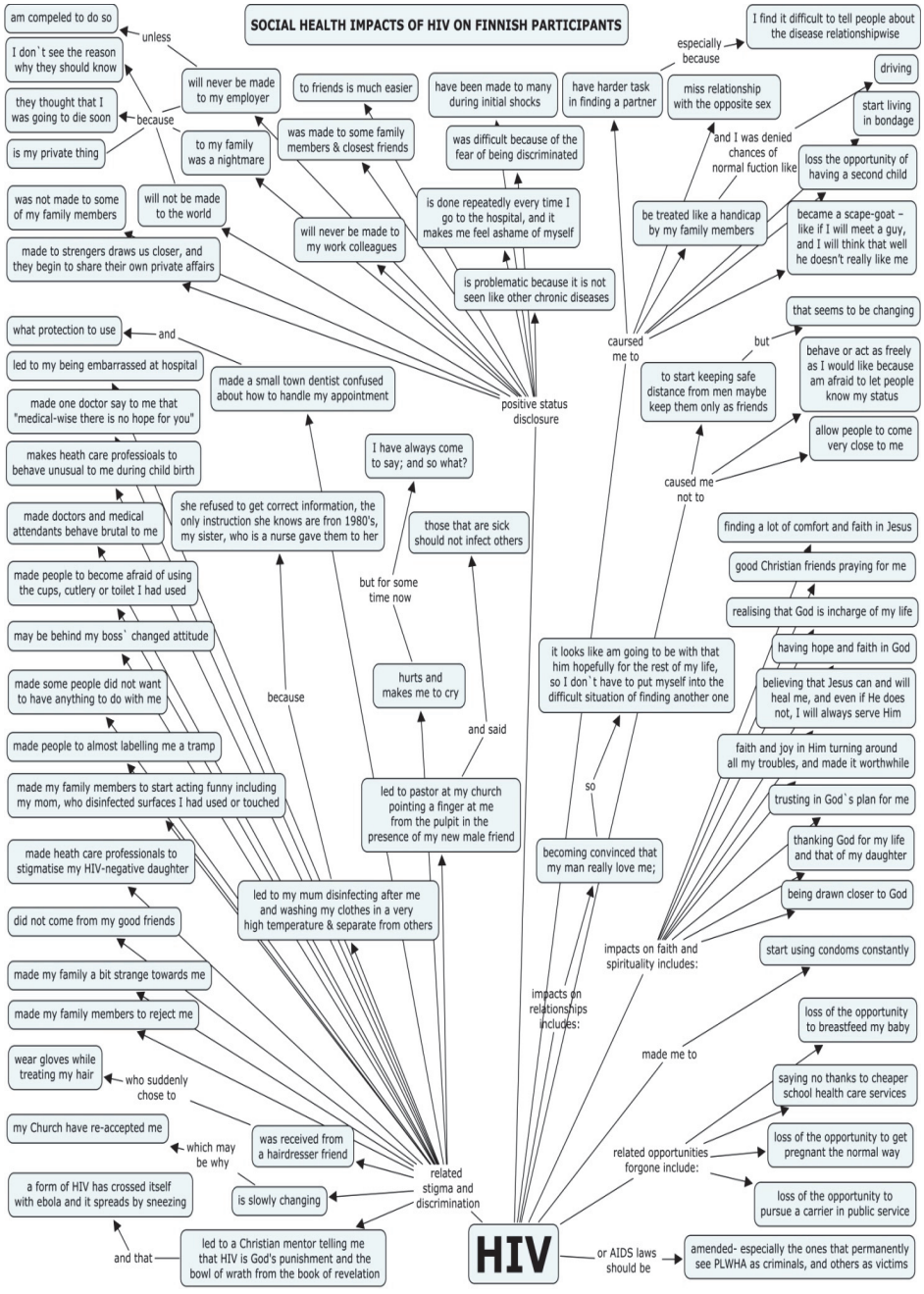


**Figure 19.** Concept Map on the impacts of HIV on the Finnish participants` social health

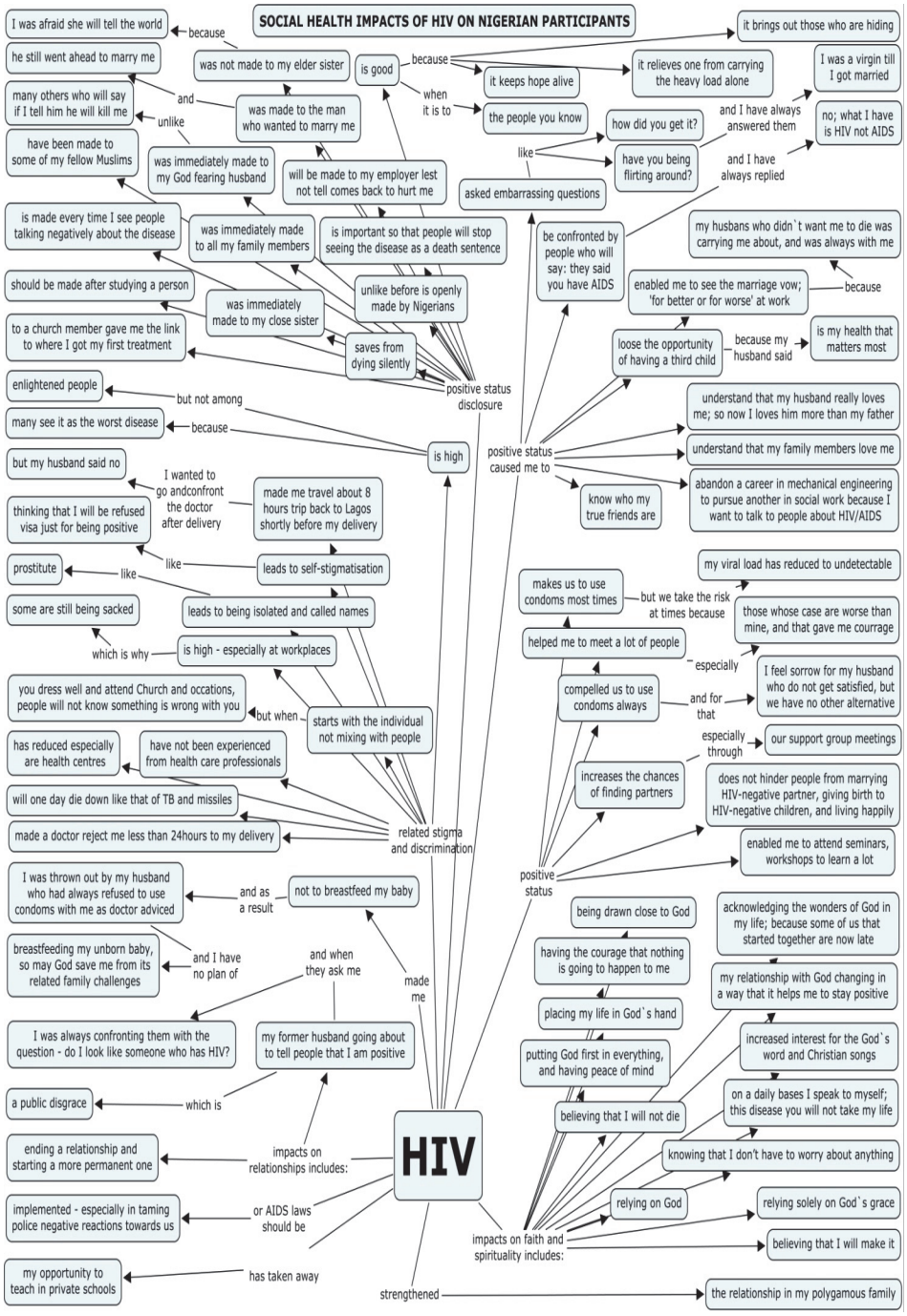


**Figure 20.** Concept Map on the impacts of HIV on the Nigerian participants` social health

## 4.5 Education-wise impacts of HIV

Besides its impacts on health, HIV/AIDS has other human impacts one of which is its impacts on education. It may not be surprising that a disease whose 11.8 million carriers are young people within ages of 15 and 24 (UNICEF, UNAIDS and WHO 2002) would seriously affect education. In fact, the disease causes double- jeopardy situation which on one hand reduces quality of education and on the other leaves fewer people able to receive the benefits of learning (WHO 2002). However, beside the education-wise negative impacts of HIV/AIDS, there are positive ones. So this category examined both the negative and positive impacts of HIV through four sub-categories as shown in figure 21 below namely: Knowledge and awareness, Experiences at school, Alterations on study plans, and Motivation for academic pursuits.

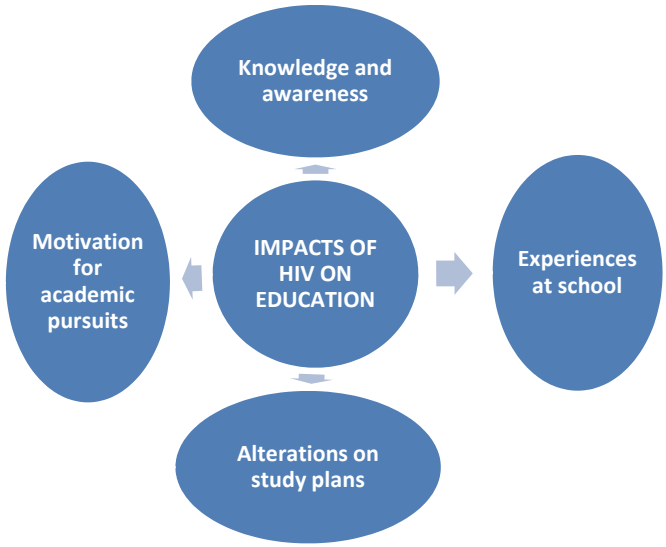


**Figure 21.** The education-wise impacts of HIV

### 4.5.1 Impacts on knowledge and awareness

As Nelson Mandela once argued, 'education is the most powerful weapon with which the world can be changed' (Bi-Botti 2009). Iit is probably the greatest empowerment every child deserves (Kelly 2000). Particularly, since the advent of internet, learning has by far gone beyond classrooms; making acquiring knowledge accessible to many if not all. Health-wise – particularly since the emergence of HIV/AIDS, the learning antennas of many who would not have cared have been raised. In this sub-category the ways in which HIV improved the knowledge and awareness of the Finnish and Nigerian participants have been explored. From the conceptions of the Finnish participants their HIV induced learning were described under the following themes: 'knowledge is power, opening of thinking faculty being exposed and informed, sex education, counselling, promotion of condoms, negative reporting, a call for studies, and a

call for tackling malnutrition'. While from the Nigerians participants they are: 'need to reach communities, drive to know, increase in knowledge, sex education, counselling, promotion of condoms, and positive reporting'.

**Knowledge is power/ Need to reach communities:** For the lack of clear understanding of what HIV/AIDS really is, many got stocked after testing positive to the disease believing that their dreams are permanently distorted, and lives smashed on concrete wall. But acknowledging that knowledge is power, a Finnish participant argues that, if such individuals could get informed, they will move on with their life, and stay healthy because the more informed one becomes is the better. Then since students seem most vulnerable to HIV/AIDS, she also advocates that schools should invite PLWHA to educate students on HIV, nevertheless, realising that Finns are generally shy, she sees her proposal as a somewhat 'mission impossible' despite the great need for it.

*Well if people are like get education they can like move on with their life, stay healthy... obviously the more information you have is better. I think it will be good if schools could like get a person to come and tell about HIV, probably someone who has it, who has lived with it, but at least in Finland I don`t know how that will be possible, who will go there actually so.... There is still some people who don`t know how you can get HIV (sh0485ff).*

Her suggestion that PLWH should champion educating pupils on HIV/AIDS is in agreement with Paxton (2002) who says that, if a person living with HIV gives sex education to students, fear and prejudice will be decreased, and the spirit of constant protective behaviour will be reinforced.

Another Finnish participant who believes that the continuous education of people will awaken their subconscious minds said, people should be repeatedly made to understand that the disease cannot be contracted through sharing toilet seats, kissing, and that the chances of living normal and long life still exist after testing positive to the disease. To her this is the best vaccination. She also encourages others to get screened for by so doing the knowledge of their status will influence their sex drive.

*Education is also something that gives you better prospects in life in a lot of ways. Information, information about it, information you don't die of it, information really that you can`t get it from toilet, you can`t get it from kissing, you can live, and also if you have it, you can live a normal life. Information about it, and education about it, and I really think that`s the best vaccination against this disease. I found out about it, it stopped me from infecting a lot people, a lot of people, and also my sexual behaviour, because I knew about it you know I didn't want anyone else to get it (sn9975ff).*

Then the third Finnish participant who sees education important because it checks some of the lingering funny beliefs and superstitions advocates that education should include teaching individuals to treat PLWHA well.

*The role of education is very important. We still deal with lots of funny beliefs and superstitions.... As well as educating people how to treat hiv positive right (ms9367ff).*

Furthermore, as in other developing countries, some communities in Nigerian remain unreached with basic facts about HIV/AIDS which is probably why more than 50% of Nigerians say they cannot shake hand, hug or share the same toilet with PLWHA (Ogunjuyigbe, Adeyemi and Obiyan 2009). As such, two of the Nigerian participants are highly in support of taking the crusade to such settings. One suggesting using diverse outreach means said:

*There is need to improve the level of awareness to the grass root. Through media! Adverts, billboards, send people to the communities; counsel people you know hold community rallies just to educate people on what HIV is all about (tp0389fn).*

The other who believes that schools should be the main target for the crusade said:

*Create awareness, let even the school age, small small ones know what HIV and AIDS is, if they have that knowledge, they will know how to take care of themselves. Even your hair you make sure you have your own something (aw0071fn).*

**Opening of thinking faculty/ Drive to know:** One of the Finnish participants believes that testing positive to HIV changed her way of thinking. As such she now sees things from different point of view; a proof of such is that she is now less judgemental.

*It has somehow opened my thinking you know, in a broader way I understand that you know tragic things happen to people you know is just, is just, is hard to describe but I think somehow it has, it has open my thinking just to higher level, I don`t know if is higher level, but personally I think am a less judgeful person because I have it (sn9975ff).*

To her Nigerian counterpart, testing positive boosted her drive to dig deeper and deeper for HIV/AIDS knowledge. She even went beyond online information and knowledge in the literature and began exploring experiences of those who tested positive before her, and her findings gave her the courage she needed to move on with her life.

*When I got to know my status, I will say that gave me the drive to want to know what HIV is really all about, you know the prone and cone of HIV, and I will tell you the best way I learned is actually through other people`s experience, so from their story you will have the courage to move on. You will know that oh yeah I really need to be strong, actually if this person survived it, then I can survive it. I learnt, went online, read few books. I read "What you need to know about HIV (tp0389fn).*

**Being exposed and informed/ Increase in knowledge:** All the three Finnish participants and two of their Nigerian counterparts argue that, living the disease exposed them intellectually. One of the Finnish participants who believes that her exposure made the disease less scary said:

*Now I was, I knew people who had it. I knew quite a lot about it, I have read a lot about it... you know really main thing about this disease is that when*

*you get information about it you see is not that scary, is not that you know, very easy to get the disease, is not something you have to be scared of (sn9975ff).*

Another said it gave her the opportunity to go for conferences beyond the shores of Finland.

*To go to Durban for a conference trip and to Dublin too (ms9367ff).*

The third Finnish participant said she now knows more individuals among the PLWHA

*...and in a way I get to know more HIV people now (sh0485ff).*

One of the two Nigerian participants who agree with them believes that the disease is good for her because testing positive gave her the opportunity to deeply explore the disease though attending seminars and workshops. It also aided her knowing more individuals.

*Emm it helped me to improve my knowledge on what the virus is all about.... I attended seminars, workshops to learn. It`s very good for me, is very good for me, it helped me to know more people (tp0389fn).*

The second said after she tested positive to HIV, the first step she took was to explore the disease which wants to kill her. As such, she scrolled through the internet in search for information on the disease. She subsequently got access to a Nigerian based HIV organisation she volunteered for, where she received life changing experiences.

*When I knew my status, the first thing I did was to find out about the disease that want to kill me. So I went into the internet, then I was at year two at (name of the school withheld). So I went through the internet find out about HIV, find out about organisation in Lagos that I can volunteer for (ht0484fn).*

**Sex education:** To transform HIV/AIDS epidemics, young people need to be equipped with the knowledge and skills for protecting themselves against HIV and other STIs (WHO 2002). Unlike in Nigeria where it is culturally and religiously unacceptable to talk to children about sex, one of the Finnish participants said she started to know about HIV/AIDS while she was still in grade four, nevertheless, most of what she now knows about HIV/AIDS is not from school because her teacher in charge of sex education did not teach it wilfully.

*One was maybe 4th grade, then maybe 7$^{th}$ or 8$^{th}$.... the education I have gotten is not really from school, is from other sources you know is at that time I don't think, I think there was a teacher who really like blushing and you know to just wanna do this, get it done with the students as possible (sn9975ff).*

Another Finnish participant said it will take in-depth sex education accompanied with reduced promiscuous sex to check the spread of HIV.

*I think sex education and returning to fidelity in marriages would keep it abay. Did't they do a program like that in Uganda, which reduced the new infections drasticly? Reducing promiscuiety, proper knowledge how hiv spreads, correct use of condoms and female condoms (ms9367ff).*

Then a Nigerian participant who supports the later suggests that individuals should learn essence of faithfulness to their spouses as a means of checking the spread of HIV.

*Be faithful to your spouse, as you know your status, you don't know the status of others, so try and protect yourself and also the other person (tp0389fn).*

Then contrary to the Nigerian norm, another participant said she gives her 12 and 17 years old children sex education.

*Like my own daughter she is 12, the other one is 17. I educate them, the only thing is to give them the foundation, it does not mean they will go out and start making up themselves. You educate them how to abstain for the young ones, but for the adult ones that are sexually active, you introduce condom (aw0071fn).*

**Counselling:** A Finnish participant said, after she tested positive to HIV, she was accompanied by one of the health professional who screened her to a clinic where she received counselling from a psychologist and a doctor.

*The clinic that tested me said, 'now you will get a time from this clinic', and it was like one week after that or something ...and the people who tested me, the woman she came with me to the clinic ...I was offered counselling from a psychologist, I got counselling from doctors ...from professional people saying hey this disease won`t affect your life if you don't want it to affect it (sn9975ff).*

Another suggests that counselling among other positive approaches should be improved.

*I would like more (spiritual) counceling, not judging. Freedom of opinion (ms9367ff).*

Then the four Nigerian participants argue they have been positively influenced by the counselling they received. One of them who seriously wanted to fight the boyfriend she believes infected her said, her being counselled to do otherwise has help her in living positively and healthfully.

*As a matter of fact she told me don't border just accept it, don't try to fight it such as to know where it came from, just let it go, and I was like fine, I stopped bordering. The doctor advised me, counselled me about taught me about the healthy living things; eating well, positive living advise you know, he taught me a whole lot, and I was like waoh (surprise) is not really a big deal after all (tp0389fn).*

Another said her doctor counselled her to eat good food, take care of herself, and not to breastfeed her baby.

> *The doctor here at Lagos then knew about it, he only instruct me – take good care of yourself, eat good food, make sure when you have the baby, you are not going to breast feed the baby (aw0071fn).*

Yet another who was at first worried about her testing positive was made to realise that it does not mark the end of her life. Now she has taken it upon herself to counsel others especially those who newly test positive to the disease. Her counselling style includes talking about how she had lived with the disease for 8 years; and by showing her picture then which when compared with her present look proofs that the disease has not changed her look. As she claimed, the style has brought peace of mind to many troubled minds especially among the newly confirmed HIV-positive individuals.

> *Finally I met the counsellor, while she counselled me, talk to me that HIV is not the end of the world, you can move on with your life and all that. Now I like to counsel people, if I see, even at Island maternity, if I see people crying I call them and talk to them – why are you crying? I have been living with it for the past 8 years nothing has …I show them my picture then and my picture now, look at me. All of them will clean their face (as0481fn).*

The forth Nigerian participant said, she was counselled by a HIV-positive counsellor whom she at first doubted her status.

> *I met a wonderful counsellor and she was also positive, although when she told me she was also positive [I beg she just dey tell me so that I will feel alright], by the end of the day she invited me to their support group (ht0484fn).*

**Promotion of condoms:** Though recent studies suggest that male circumcision may reduce the risk of acquiring HIV though sex (WHO 2010b), it remains the failure of many to see themselves within the high-risk group, and commit to safe sex that often facilitate the spread of HIV and STIs (Durojaiye 2011). As such, abstinence or the use of condoms remains the most effective ways of preventing HIV and STIs (WHO 2010b). So, since the importance of condoms is second only to abstinence, overwhelmingly all the Finnish and Nigerian participants support its promotion. One of the Finnish participants who does not see such the same as promotion of promiscuous sex said:

> *I don't think that promoting it is promoting promiscuous sex, it`s promoting something good, you know the world we live in is very sexual. Sex is a natural thing, but also you know a lot of things are sexualised but I really don't think condom is you know, I don't think there is anything bad in it (sn9975ff).*

Another Finnish participant who believes that many lack necessary self-control to overcome sexual desire suggests that condoms should even be handed out free.

*If you MUST do it, use a condom. People will always do it anyhow, so free condoms should be available. Giving more kondoms free (ms9367ff).*

The third Finnish participant who believes that, it is ridiculous that churches in Africa argue that giving out free condoms motivates sexual urges said:

*Mainly not good church stuff that not using condom thing like you know save yourself for marriage because many time, just it doesn`t happen so, I think that`s a really big problem especially I think it isn`t like church in many places in Africa or so going around and saying like you know don`t use condom, just don`t have sex and stuffs, it`s just ridiculous.... Yeah, because people have sex.... Well, I think that everyone should have a lot of condoms, always, everywhere because you never know. People have sex, in a bit of the moment things happen; it will be nice to have a condom. I don`t believe that you know is a total rubbish that if you give out condoms people will like have more sex, is just people have sex, when they have any way to have sex, it will be nice they use condom, so hand them out everywhere, I think that will be a good idea (sh0485ff).*

Then among the Nigerians participants, the one who personally promotes condoms said:

*Condom is good, it protect, is good, I will promote it. I talk to people use condom, if you are not ready (as0481fn).*

Another Nigerian participant who sees it as a way of protecting young people said:

*There is need to promote condoms. Young people are having sex, despite all our knowing that having it without condom, and they don't know their HIV status, they don't know their partner`s HIV status, so really for me there is need to promote condoms (ht0484fn).*

The third who believes that the level of awareness has made it appear less the promotion of promiscuous sex or immorality said:

*Yes, because giving out condoms is in a way saying lets, if you can`t abstain from sex then use the thing. I think with the level of awareness here now, people no longer see it as a way of promoting sex or immorality, no! (tp0389fn).*

Then the fourth who is concerned about the safety of women in polygamous marriages said:

*Is a good idea, you know Christians go against it, that if you are giving free condom, you are encouraging sex. But since the situation is like this, we cannot sit down and fold our legs. We have sexually active people in the society. Whereby you don't use the male condom, there is female condom for you to use protect yourself. Like those men that has two or three wives, when they get disease if they are not using condom, it start with one person and it goes round the whole women in the house which is not supposed to be so (aw0071fn).*

**Negative reporting/ Positive reporting:** It has been established that there is a link between AIDS media coverage and AIDS suicides (Aro et al. 1995). In the case of Finland, prior to the confirmation of the first AIDS case in June, 1983, over 50 articles were published on AIDS painting deadly and fearful picture of the disease like: "*AIDS devours its victims before your very eyes AIDS*" (Clarke 2004, 222). The period was characterised with media '*busy body'*, and Journalists were constantly seen around hospitals in search for the opportunity to take the picture of someone with AIDS (Ibid). Now though the media HIV/AIDS reporting are much better, yet two of the Finnish participants still believe that as far as HIV/AIDS is concerned, what makes the news in Finland are the ugly sides of the disease which are often partially and wrongfully reported. One of the two who sees the partial reporting to be unethical said:

> *I think the way is portrayed in media is really not ethical...; the media use it as something you know, like for the wrong intentions the way is portrayed sometimes. the media portray HIV-positive people as evil people who want everyone else to get this disease, yes that`s that`s the point.... Well, the media only tells one part of the story, you know is really not, the media should not say anyone`s name, or anyone`s faces, you know not recognisable facts you know, I really think the media has no social responsibility to to tell people, and also show the two sides of the story (sn9975ff).*

The other who believes that the media adds to the burdens of PLWHA in Finland said:

> *The only thing I have noticed in the media is, people who have infected someone and their faces, names and everything have been like published in the newspapers so that everyone can see that [oh] this person has HIV and has slept with someone – oh my God. So I think that it`s really outrageous how the media works here.... I think the media is doing wrong, what the media is doing is criminal and shouldn`t be allowed.... every HIV person in Finland have been afraid that you know if something happen is my face that is going to be in the newspaper (sh0485ff).*

But fortunately the Nigerian participants see their case to be a reverse of the Finns. As two of them expressed it, the Nigerian media is PLWHA friendly, as such her reports are not aimed at hurting or worsening the conditions of the PLWHA in Nigeria. One of the thumb-up remarks says:

> *Like in the morning after listening to the news, they say HIV/AIDS is real, something like that. I have forgotten the term they normally use in the morning after listening to the news. So at times you go, there is always some cartoon they put at the Punch (name of a daily tabloid), that is passing the message to people, even some children – at times when you read some cartoon of children, they still use that to pass the message to children. So they are really trying, they are really trying. Even for children you will see some short short firm they show (aw0071fn).*

Another Nigerian pinpointing at the TV broadcasting stations` suggests that, since they are the main source of news, they should always report the disease in interesting manners in order to arouse people`s desire to know.

*They should build their capacity in reporting HIV/AIDS so that they will report issues as they are. Because what they, what people will be listening to, some people don't have how to connect to internet, some don't do anything even maybe buy film to watch on HIV. May be they just tuned the TV and they are talking about HIV/AIDS. It depend on how the message is being related that is when they will listen. So the media have an important role to play. They must build their own capacity then pass the information in the right way and manner (ht0484fn).*

**A call for studies:** In view of the need for many to have full understanding of who the PLWHA really are, a Finnish participant suggests unbiased inquiries which look beyond their being tagged drug addicts, prostitutes, homosexuals, and so forth.

*You know, if you have some relative or close person or someone in your work or studies who are interested in it, maybe you start researching hey who are this people, not just bad people, drug addicts, homosexuals, you know prostitutes whatever (sn9975ff).*

**A call for tackling malnutrition:** Wherever the access to food is scarce, the prevalence of HIV seems alarmingly high (WHO 2002). This may have contributed to the reason why most of the PLWHA are found in the third world countries. So besides HIV/AIDS itself, inaccessibility to food or malnutrition poses treats, and for this reason a Finnish participant recounting from the experience of her HIV-positive friend on a missionary crusade in Malawi argues that, malnutrition is a bigger health problem than HIV/AIDS, as such, she suggests that in less privileged settings malnutrition should be tackled first.

*Malnutrition sshould be dealt with first in order to gain full benefit from the treatment. My friend works as a missionary in Malawi.She is positive, she has formed hiv- education groups. She says that thebiggest problem is malnutrition.Not hiv/ aids (ms9367ff).*

### 4.5.2 Summary of impacts on knowledge and awareness

In this sub-category a total of 16 themes (9 and 7 from the Finnish and the Nigerian participants respectively) emerged on to what extent living with HIV has influenced participants` knowledge and awareness. On the overall, there are strong one-on-one concord between 7 of the Finnish group`s themes and that of the Nigerian group. They show that, in acknowledgement that knowledge is power, Finnish participants expressed their desire to see everyone equipped with facts on HIV/AIDS. One even envisages that PLWHA should in their wealth of knowledge begin to visit schools to educate students, but acknowledging the shyness of Finns, she sees it is a mission impossible. A Nigerian participant said knowing her positive status gave her the opportunity to broadly explore the disease especially through other people`s experiences. In like manner,

the three Finns said living with the disease really exposed them intellectually. For while it made the disease less scary to one, to another it gave her the opportunity to attend conferences beyond the shores of Finland, then to the third it gave the opportunity to know more people, and two of the Nigerians agree with them. One of the Finnish participants said it also changed her way of thinking to the point that she is now less judgemental.

Then unlike in Nigeria where it is culturally and religiously unpopular to give sex education to children, in Finland it is a common norm especially at schools, which is why one of the Finnish participants said she started to know about HIV/AIDS even while she was still in fourth grade. Another suggests that in order to check the spread of HIV, marriage fidelity should be promoted as well, and the idea was supported by one of the Nigerian participants. Then contrary to the Nigerian norm, a Nigerian participant said she gives her 12 and 17 years old children sex education at home. Both the Finnish and Nigerian participants said they received counselling especially shortly after testing positive to HIV. But what seems unusual is that one of the Nigerian participants said she has taken it upon herself to counsel especially those who newly test positive to the disease. Her counselling style includes informing them that she had lived with the disease for 8 years, then by showing them her picture before the diagnosis which when compared with her present look proofs that the disease has not changed her look; and as she claimed, the style has brought peace of mind to many troubled newly confirmed HIV-positive individuals.

Furthermore, since condom is second only to abstinence as far as preventing HIV and STIs are concerned (WHO 2010b), overwhelmingly all the participants support its promotion despite the fact that many church leaders see it as the promotion of promiscuous sex. Then because in some community settings in Nigerian as in other developing countries, there are still lacks of basic knowledge on HIV/AIDS, two of the Nigerian participants suggest that the crusade against HIV/AIDS illiteracy should be taken to local community settings. Then while all the Finnish participants bitterly complained about partial and unethical reporting of the Finnish media against HIV/AIDS and the PLWHA, their Nigerian counterparts gave their media thumb-up for positive reporting and contributing to the creation of HIV/AIDS awareness. Furthermore, in view of the need for many to have full understanding of who the PLWHA really are, a Finnish participant suggested a close unbiased inquiry which will look beyond their being tagged drug addicts, prostitutes, homosexuals, and so forth. Then believing that in the third world countries malnutrition is a bigger health problem than HIV/AIDS itself, a Finnish participant suggests that it should be tackled first in such settings.

So except for the differences in giving sex education to children and the negative versus positive media reporting, it seems living with the disease increased the knowledge and awareness of both Finnish and Nigerian participants. For further insight, concept maps in figures 22 and 23 in pages 165 and 166 separately mapped out the overall impacts of HIV on education as experienced by the Finnish and Nigerian participants, and table 24 in appendix V shows the comparison between the Finnish and Nigerian participants` conceptions on the effects of HIV on knowledge and awareness, and the comparison was backed

with findings from earlier studies. The next sub-category explored the experiences of participants at school.

### 4.5.3 Experiences at school

This sub-category explored the Finnish and Nigerian participants` experiences at their schools after testing positive to HIV. Although there seem not to be many responses on their experiences at school probably because most of them have been hiding their HIV-positive status from their colleagues and school staff, nevertheless, the few responses seem very educative. The Finnish participants experiences were explored under two themes namely: 'no disclosure at school, and embarrassments at school', while that of their Nigerian counterparts were explored under three themes namely: 'confining on school doctor, becoming famous for disclosing at school, and normal life in campus'.

**No disclosure at school/ Confining on school doctor:** Two of the Finnish participants are not interested in disclosing their positive status at school. One of them whose decision is because the disease is highly stigmatised said:

> *Is still very stigmatising and is something I will never tell any of my student fellow student never! I will never tell any teacher in my school (sn9975ff).*

The other questions why she should disclose her status at school when other chronically ill students with diseases like diabetics do not.

> *I don`t want to be public about it, and also I don`t see any reason why people in the university or anyone should know I have HIV, like some people will have like diabetes, I just don`t see like that there will be any connection, why would they have to know about it? (sh0485ff).*

But beside the reasons they gave, it seems the unwillingness could have also been propelled by the relative peace they enjoy for not telling, and the lack of reward for doing so; for individuals tend to disclose personal information out of distress and expectance of some kind of benefit (Pennebaker and Beall 1986, Greenberg and Stone 1992, Derlega, Metts, Petronio and Margulis 1993, Kalichman, DiMarco, Austin, Luke and DiFonzo 2003).

However, one of the Nigerian participants extensively narrated how she disclosed her positive status to a school doctor out of distress and expectation of some kind of protection. According to this participant it was during the medical screening prior to her university admission that out of the fear of being denied the admission she disclosed to one of her school doctors, but she later realised that HIV screening was not even part of the required medical examinations. Nevertheless, the good relationship which the disclosure established between them has been very rewarding to her.

> *And I didn't like to like blow the trumpet – Hey guys am HIV-positive, I didn't have to blow the trumpet, you know I look well, I look healthy, so what I did was when we were going to do our medical check-up, I thought I was scared, really I was scared, then I was like will this deprive me of my education now? I knew to a little extent that being HIV-positive does not*

*mean the end. So when I was going to do my medical check-up, the normal procedure when you gain admission into a university, you have to do a medical check-up.... No, no, it does not include a HIV test, is just that the school require your medical history. When I was going to do my, I thought I was scared, I thought it include HIV test, then I was like would this mean I will be denied the admission or something, so what I did was, I met the doctor, I confined in her, I told her, I was, am HIV-positive.... Yeah, yeah, school doctor, so I told her that am HIV-positive, she was like 'really? waoh! Okay, is no big deal', you know she she she was impressed that I could even speak out, you know, and for me taking the trust in her, someone I have not known before, for me to have confined in her, she felt it was a prize, a big prize to her, so she liked me that much you know, and from time to time she call me 'how are you doing, I hope all is well?' We became very close, very very close, funny enough I found out that the medical screening did not include an HIV test. So some people, some people will run away from school (tp0389fn).*

Perhaps confining on the doctor gave her the peace she expressed above because studies show that, PLWHA who disclose their positive status demonstrate normal immune function and are less likely to frequent hospital than those who hide theirs (Pennebaker, Colder and Sharp 1990), because suppressing thoughts on difficult experience increases stress (Greenberg and Stone 1992).

**Embarrassments at school/ Becoming famous for disclosing at school:** A Finnish participant who`s positive status leaked at school was twice embarrassed; first by a fellow student who during a physical exercise refused to touch her, and later by a teacher who asked her if she was still capable of learning.

*At school it somehow leaked out that I was positive. Once we had an exercise where we had to take each other from hands, ears, nose... one girl with a large discusted gesture refused to touch me. Once a teacher asked whether I was still capable of learning? I don't know why, but I suspect that she must have been told (ms9367ff).*

To minimise such challenges, Chilisa, Bennell and Hyde (2001) recommend that university environments should be made HIV/AIDS friendly. Another Finnish participant who also advocates for HIV/AIDS friendly school environment said:

*I need maybe the just to know that HIV-positive friendly environment, or whenever just to know that they don't discriminate on the basis of it (sn9975ff).*

Furthermore, Chilisa, Bennell and Hyde (2001) recommend that modules should be amended in a way that those students who cannot attend classes regularly may duly benefit. But contrary to the above Finnish participant experiences, a Nigerian participant said she was never discriminated at school, instead the public disclosure of her positive status at school made her famous.

*And they never discriminated me, not at all, not even from a student. Like I told you is what you feel, is what you feel. If you are doing something and I don't see what you are doing, for me I don't feel it.... they may talk at the back or whatever, I didn't hear any rumour, even when you entry (name of her school withheld) that time, even to 2010, and ask for my name; people know me... that`s the girl that declared her status in school, you understand? So I was even known for that, I became popular for that (ht0484fn).*

**Normal life in campus:** Then the Nigerian participant who confined on her school doctor said, she is in her final year and will be graduating soon, and throughout her university school years, she lived normal life because she never saw the disease as a challenge.

*I thank God that am in my final year today. In couple of weeks time I will be writing my final exams. I am done with my project, I lived my normal life in the campus like every other normal student, HIV did not stop me from school, I didn't see that as a challenge. As a matter of fact I leant more when I got to know that am HIV-positive (tp0389fn).*

Chilisa, Bennell and Hyde (2001) also recommend positive living with the disease as a coping strategy within and outside school campus.

### 4.5.4 Summary of experiences at school

In this sub-category a total of 5 themes (2 and 3 from the Finnish and the Nigerian participants respectively) emerged illustrating the experiences of participants at school. They reveal that for the fear of being stigmatised, the Finnish participants have no plan of disclosing their HIV-positive status at school. However, one of them who`s positive status leaked at her school was twice embarrassed by a fellow student and a teacher. Then from the Nigerians` side; while one of the participants out of fear of being refused admission disclosed her positive status to a school doctor, (but later realized that HIV screening was not even an admission requirement), another became famous at her school for publicly disclosing her positive status. Then the one who confined on her school doctor said, her HIV-positive status has not affected her living normal life because she never saw the disease as a big challenge. Each of the two Finnish group`s themes are in concord with two of the Nigerian group, and the responses in this sub-category also show that the Nigerian participants are more positive about their status than their Finnish counterparts.

For further insight, concept maps in figures 22 and 23 in pages 165 and 166 separately mapped out the overall impacts of HIV on education as experienced by the Finnish and Nigerian participants, and table 25 in appendix V shows the comparison between the Finnish and Nigerian participants` experiences at school, and the comparison was backed with findings from earlier studies The next sub-category explored how the participants` studies were altered by the positive status.

### 4.5.5 Alterations on study plans

Since HIV/AIDS causes double-jeopardy situation which on one hand reduces the quality of education, and on the other leaves fewer people able to receive the benefits of learning (WHO 2002), this sub-category examined how the disease has affected the studies of the participant. The themes under which the Finnish participants` experiences were explored are: 'delayed university enrolment, drop-out for one semester, out of school for four years, learning disabilities, reduced IQ, and not sure'. While those of the Nigerians participants are: 'change of school choice, extra semester in school, nine years away from school, forgetfulness and request for a break, reading just two days to exam, falling sick after each exam, and no barrier to studying and working'.

**Delayed university enrolment/ Change of school choice:** While Chilisa, Bennell and Hyde (2001) observed that HIV/AIDS attrition reduces university enrolment rates; a 36 years old Finnish participant whose university enrolment was delayed said she is not sure the disease is the main culprit for that because she was also using drugs.

*Well, I can`t really say because I was using drugs, I wasn't thinking about any university at all, so! (sn9975ff).*

Then her Nigerian counterpart on the other hand said, she had made every preparation to attend the university in her home state (name of the state withheld), but when she tested positive to HIV her dad advised her to search for another school in Lagos which will keep her close to a support group.

*Planning to go back to (name of the university withheld) (which is a university in her own state), I have to forget about it, so I needed to, my dad said I needed to be in Lagos where I could be close to this people, to talk to, to ask questions whenever I needed to. And then I got a form in another school here in Lagos (tp0389fn).*

**Drop-out for one semester/ Extra semester in school:** According to Kelly (2001), HIV/AIDS affects the demand and supply of education, as such; testing positive to the disease caused a Finnish participant and a Nigerian participant to spend additional semester in school. For the Finn it was due to depression and confusion on whether to continue her studies or not.

*When I got that diagnose then I didn`t know like what was happening, and then I took like one term off, I didn`t do anything just to figure things out (Was there a thought of ending your academic career?) Yeah, because when I just came to my senses, it was just brief period of depression and all that you know after that when I decided that okay life goes on, and I want to do something with my life, then it was just more easier for me to study. I just dropped everything and try to put couple of months. I think that was really good because after that I was like waooh waooh, now I want to start life again (sh0485ff).*

But for the Nigerian participant it was due to serious illness which did not allow her to write her exams.

*An extra semester in school. I was sick, even that time I was going; there was a day I went for exam and inside the exam hall I could not write anything, when the examiner came to my table, I put my head on the table and when he came and touch me, I was like "who allowed you in?" I was hot, hot. He was like who allow you in, then I have to get out of the exam hall because I can`t do anything (ht0484fn).*

**Out of school for four years/ Nine years away from school:** Again in line with the study of Chilisa, Bennell and Hyde (2001) the which reveal that HIV/AIDS related stress influences withdrawal from school, a Finnish and a Nigerian participants` tertiary education was delayed for four years and nine years respectively. The Finnish participant said she would have quitted her studies completely if not that she loves studying, and also takes pride in finishing what she had starts. She still wants to further her education, but her full time job is the main barrier.

*Hiv paralized me for 4 more years but the I decided to study even though it was a death sentence those days. I just kind of had faith and hope. Besides I enjoy studying. Decided I would lead my life as normally as I could. Slowly I am working my up. I am thinking of getting a masters degree or studying something else. However I have a permanent full time job now and my wages are relatively good. Sometimes I have been tired but I have never been a quitter and I have generally finished what I start. I Take pride in that (ms9367ff).*

Then the teacher in training Nigerian participant who skipped school for nine years said she had finished the first part of her programme TTC (Teachers` Training College), and was already in the second part: NCE (National Certificate of Education) when HIV related constant illness did not allow her to continue her studies, but she resumed in 2010, but still finds it difficult to cope.

*Then I have finished the TTC, I have started my NCE, but the illness was coming often and on, then I couldn't continue. So I have to stop education – the NCE. I started with the NCE then I stopped because of constant illness. I started this the NCE course this time around – that was year 2010, I missed school for long i.e. 9 year. I missed school for long, even when I started it was very difficult to adjust (aw0071fn).*

**Learning disabilities/ Forgetfulness and request for a break:** While a Finnish participant claims that she developed learning disability due to the side-effects of the HIV medications.

*Learning disabilities. Due to side effects of the medicine used to treat hiv (ms9367ff).*

One of her Nigerian counterpart claims that her own medications makes her forget easily, which is why at a point she requested for a study break through her supervisor.

*The bad it (HIV medications) has done is that it makes me to forget easily. Like now we may be talking if it get to a point I will forget what I want to say, and later I will recollect. Because you know this drugs we are taking at times always has effect on your, your, I will say thinking, it makes you forget, but later you will recollect. It got to a point that one day I called our supervisor I said sir [I did not disclose my status], I said sir – I find it very hard to assimilate, how am I going to cope? The man said – if you are going to have a break, of course you will have to (aw0071fn).*

**Reduced IQ/ Reading just two days to exam:** A Finnish participant who claims that she uses to be a bright student said now she has trouble remembering and also finds it difficult to picture large objects.

*I was a bright student before, I had no trouble remembering nor picturing large entities. Now I am average with hard work. I have trouble remembering and picturing things. I am slow... (ms9367ff).*

Then her Nigerian counterpart claims that, she can now only read about two days exams because her brain can no longer retain things properly.

*I can`t read, like if we are going to have exam like next week now, what I will do, I will have to read maybe two days to the exam. I don't read a week before the exam, because I will forget. So I read two day to the exam so that the thing will be fresh on my brain (aw0071fn).*

**Falling sick after each exam**: Again the Nigerian participant who had lived with the disease for about 13 years and can read only but two days to exam claims that she also falls sick after each exam period due to the inability of her body to withstand examination stresses.

*So the stress, and is always very difficult, been HIV positive is not easy, is very difficult towards the exam is very stressful, and after each exam, I always fall sick, after each semester, to me I don't know about others (aw0071fn).*

**Not sure/ No barrier to studying:** But contrary to the earlier responses, a Finnish participant said she is not sure the disease has negatively affected her studies, for she has had it long enough to be at peace with it, instead it gave her the urge to study.

*I don't think it has [affected me academically]. I have had this disease for a long time, I have had all these years to you know think about it and come to peace with it.... Well, now am really very enthusiastic about it (studying), but maybe because I have seen life, and now I really want to, I really have this urge (sn9975ff).*

Furthermore, two of the Nigerian participants similarly argued that the disease has not really had negative effects on their academic pursuits. For one, the only point where it almost affected her was when she started her medications. When it made her somewhat sick and drowsy, but it did not affect her studies because she started it during a holiday.

*At a point when it should have affected my academics work load was when I started drugs (medications) ...initially when I started, the drug make me sick, it makes me drowsy, that is why I said at a point when it should have affected my study I was on break (tp0389fn).*

Then the other out rightly claimed that it never affected her studies.

*HIV did not stop them from going to school. You can be a graduate, they can work in anywhere; they can work in bank, in any society (as0481fn).*

### 4.5.6 Summary of alterations on study plans

In this sub-category a total of 13 themes (6 and 7 from the Finnish and the Nigerian participants respectively) emerged on the alterations living with HIV has made in the participants` academic pursuits. The themes revealed that HIV effects on school enrolment seems uncertain, but it caused a Nigerian participant the opportunity of studying in her first choice university. Then the academic pursuit of a Finnish and a Nigerian participant were extended by a semester; for while the Finn dropped-out due to depressed feelings and contemplation on whether to continue her studies or not, the Nigerian`s was due to illness which did not allow her to sit for exams. Then for similar reason another Finnish and Nigerian participant skipped school for four and nine years respectively. Nevertheless, the Finn said she was able to return to school because she loves studying, and takes pride in finishing what she started. While as the Nigerian claimed that she dropped-out due to frequent illness, then since her resumption in 2010, she has been struggling to cope.

Pin-pointing on the side-effects of her HIV medications, a Finnish participant claimed that, she has now developed some level of learning disabilities because her IQ has been reduced, as such, she has trouble in remembering, and finds it difficult to picture large images. Similarly, her Nigerian counterpart said the side-effects of her medications makes her to forget easily which is why she can only read two days to her exams less she forget, and she also does fall sick after each semester exam period. But contrary to the earlier responses, a Finnish participant claimed that she is not sure the disease has negatively affected her studies because she has had it long enough to have come to peace with it. Then in addition, two of their Nigerian counterparts similarly argue that the disease has not really affected them academically.

So based on the participants` responses, it seems the disease affects academic pursuits especially due health effects of HIV medications. But it is uncertain whether it is as a result of how long the medications have been taken or because the side-effects of the earlier medications were worse than the recent ones. Then while the disease`s effects on the academic pursuits of the Finnish participants are more emotional health related, those of the Nigerians are chiefly physical health related. For further insight, concept maps in figures 22 and 23 in pages 165 and 166 separately mapped out the overall impacts of HIV on education as experienced by the Finnish and Nigerian participants, and table 26 in appendix V shows the comparison between the Finnish and Nigerian participants` experiences with HIV related alteration of academic pursuits, and the comparison was

backed with findings from earlier studies. The next sub-category explored how testing positive to the disease motivated participants` desire to study.

### 4.5.7 Motivations for academic pursuits

As demonstrated by one of the Finnish participants in the last sub-category; testing positive to HIV also boosted her zeal to study, as such, this sub-category examine proper how the participants` positive status had motivated their academic pursuits. Of course, this is in contrast with the 132 University of Botswana`s students who were asked to withdraw from school due to reasons which includes poor health (Chilisa, Bennell and Hyde 2001). The themes under which the Finnish participants` responses were explored are: 'hey I can do it, and a push to study fast. While those of the Nigerian participants are: 'going back to school, stronger drive to study, a push to study harder, and switching from mechanical engineering to social science'.

**Hey I can do it/ Stronger drive to study:** While a Finnish participant said she is very enthusiastic about studying because she wants to proof to herself and to the world that HIV is not self-limiting.

> *...also if I want to, even if I wouldn't come public, in some way I have, I want to, I want to show me and the rest of the world [most of the world who doesn't know about it], 'hey I can do it', and this disease doesn't stop me (sn9975ff).*

Her Nigerian counterpart said that the disease has not reduced her academic strength, instead it improved her drive to study harder so as to proof to her dad that HIV did not limit her in any way.

> *HIV-positive or not, am not a dull student, HIV-positive or not, am not a dull student. So being HIV-positive did not reduce my level of academic strength in any way, I will say my drive became stronger as a matter of fact. I decided to do more to proof to my dad that HIV is not limiting me in any way. So I will say it kind of give me the drive to study harder (tp0389fn).*

**A push to study fast/ A push to study harder:** Another Finnish participant recognised testing positive to HIV as the needed kick for motivating her to study. According to this participant from childhood she had always been at the top of her class, but during her teenage she lost focus and began to contemplate lowering the pace of her study, but testing positive to HIV restored her zeal to study fast.

> *When I was younger I was really good at school, I have always been the top of my class basically, and then after teenager there was this point that I didn`t, well, I thought that there is time and I don`t know if I really want to study so fast or maybe I take some years off you know and try to do something lah lah lah, and after the diagnose it kind of like, just the speed, that process that I want to graduate and do stuff...like it really pushed me to achieve my goals like to study and start thinking what I will want to do... it just made me study. I don`t see it like affected at least negatively my study or*

*anything, just positively, just to give me the bit of kick that I sometime need (sh0485ff).*

One of her Nigerian counterpart who also believes that testing HIV-positive has positively influenced her studies, argues that it made her study harder.

*So, I will say it kind of give me the drive to study harder (tp0389fn).*

**Returning to school:** Furthermore, living with HIV compelled a Nigerian participant to return to school after she had abandoned it for 9 years. Her returned to school was primarily because she realised that in her present health condition she needs to upgrade herself academically, so as to increase her chances of finding a good job in the civil service which will in return safeguard her future.

*The foundation of the financial this thing is not strong, that is why I went back to school to upgrade my certificate, so that I can look for a better work. So whereby I didn't do that, in the future am afraid. When I finish now and get a better teaching work, maybe get a work in government Para-status (civil service) at least that is an opportunity. You know when you are no more, when you are not strong, the government will be there for you, but private sector is the one you cannot rely on (aw0071fn).*

**Switching from mechanical engineering to social science:** Then another Nigerian participant who graduated as a Mechanical Engineer has returned to school on part-time basis. She is now studying 'Sociology' because testing positive to HIV has helped her to discover a new calling in social service.

*Mechanical engineering, so when HIV came into my situation in the sense that is not as if engineering is not a fine course, but I felt like going to talk to people, going to socialise, am going to go into social work, that is why am doing social work now. For me is an opportunity to do so many things, so for me sociology is a fine course.... Am doing part-time again in school, I can be able to work other places that is why am moving up in my degree (ht0484fn).*

Of course this is in direct contrast with the response of the Finnish participant who believes that testing positive to HIV has taken away her opportunity to work in civil service.

### 4.5.8 Summary of motivations for academic pursuits

In this sub-category a total of 6 themes (2 and 4 from the Finnish and the Nigerian participants respectively) emerged illustrating HIV related motivation for academic pursuits. They reveal that while testing positive to HIV increased the enthusiasm of a Finnish participant to study, it made her Nigerian counterpart to study harder to proof that HIV is not self-limiting. Another Finnish participant acknowledged that she tested positive to HIV at a time when she needed a kick to motivate and restore her zeal to study, and the HIV-positive result did the magic. Then, though testing positive contributed greatly to a Nigerian participant dropping out of school for 9 years, but seeing her future through HIV related illness motivated her to return to school in order to safeguard her future. Then another Nigerian participant who graduated as a 'Mechanical Engineer'

returned to school to study ‘Sociology’ because testing positive to HIV gave her a new calling in social service. So, while for the participants from both countries, living with HIV further propelled their zeal to study, the enthusiasm seems more in the Nigerian participants.

For further insight, concept maps in figures 22 and 23 below separately mapped out the overall impacts of HIV on education as experienced by the Finnish and Nigerian participants, and table 27 in appendix V shows the comparison between the Finnish and Nigerian participants` HIV related motivation for academic pursuits, and the comparison was backed with findings from earlier studies. This is the end of category five on the impacts of HIV on education (consisting of 4 sub-categories and 40 themes – 19 and 21 on the Finnish and the Nigerian participants` conceptions); the next category explored the impacts of HIV on productivity and future goals.

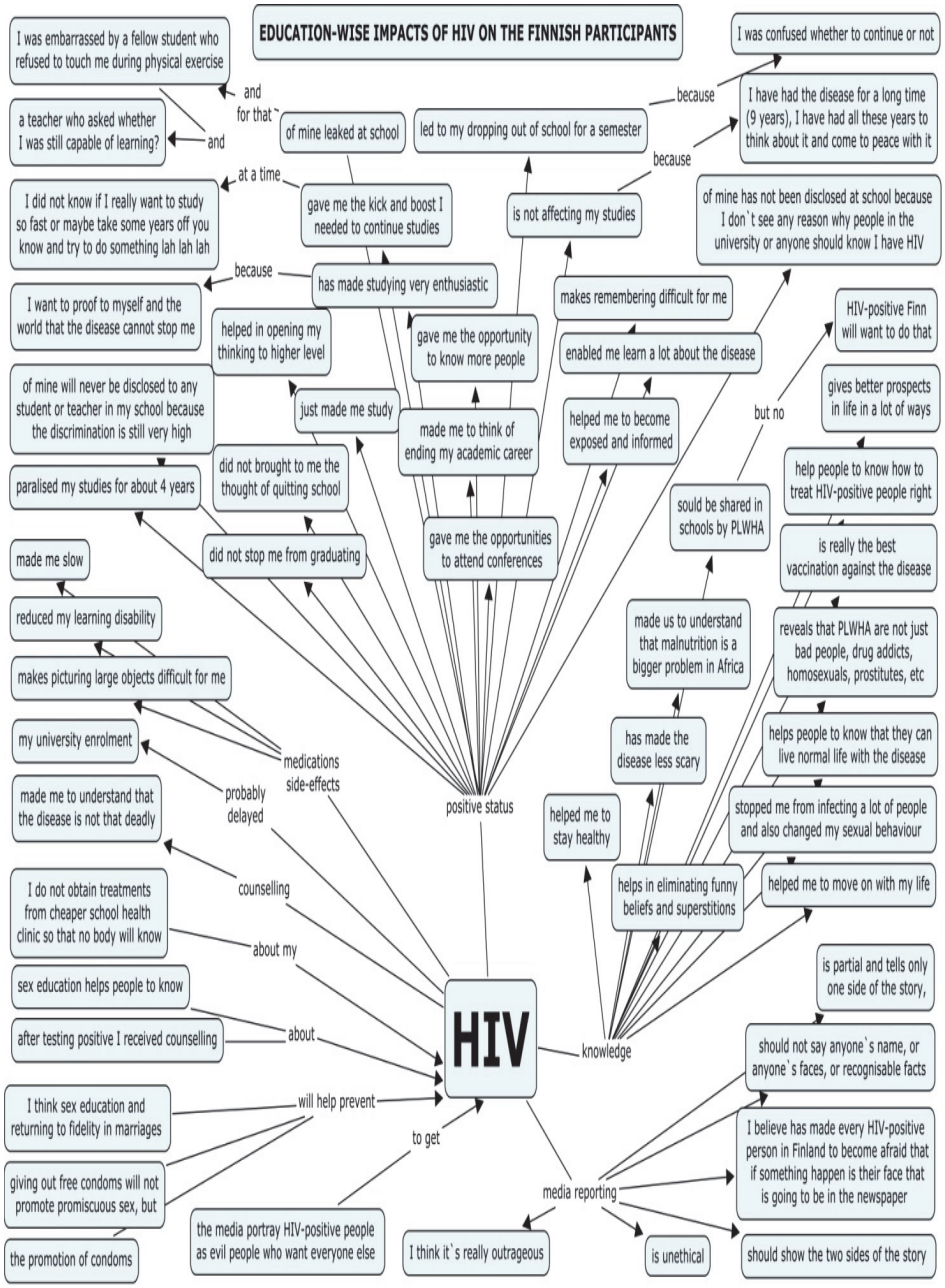


**Figure 22.** Concept Map on the impacts of HIV on the Finnish participants' education

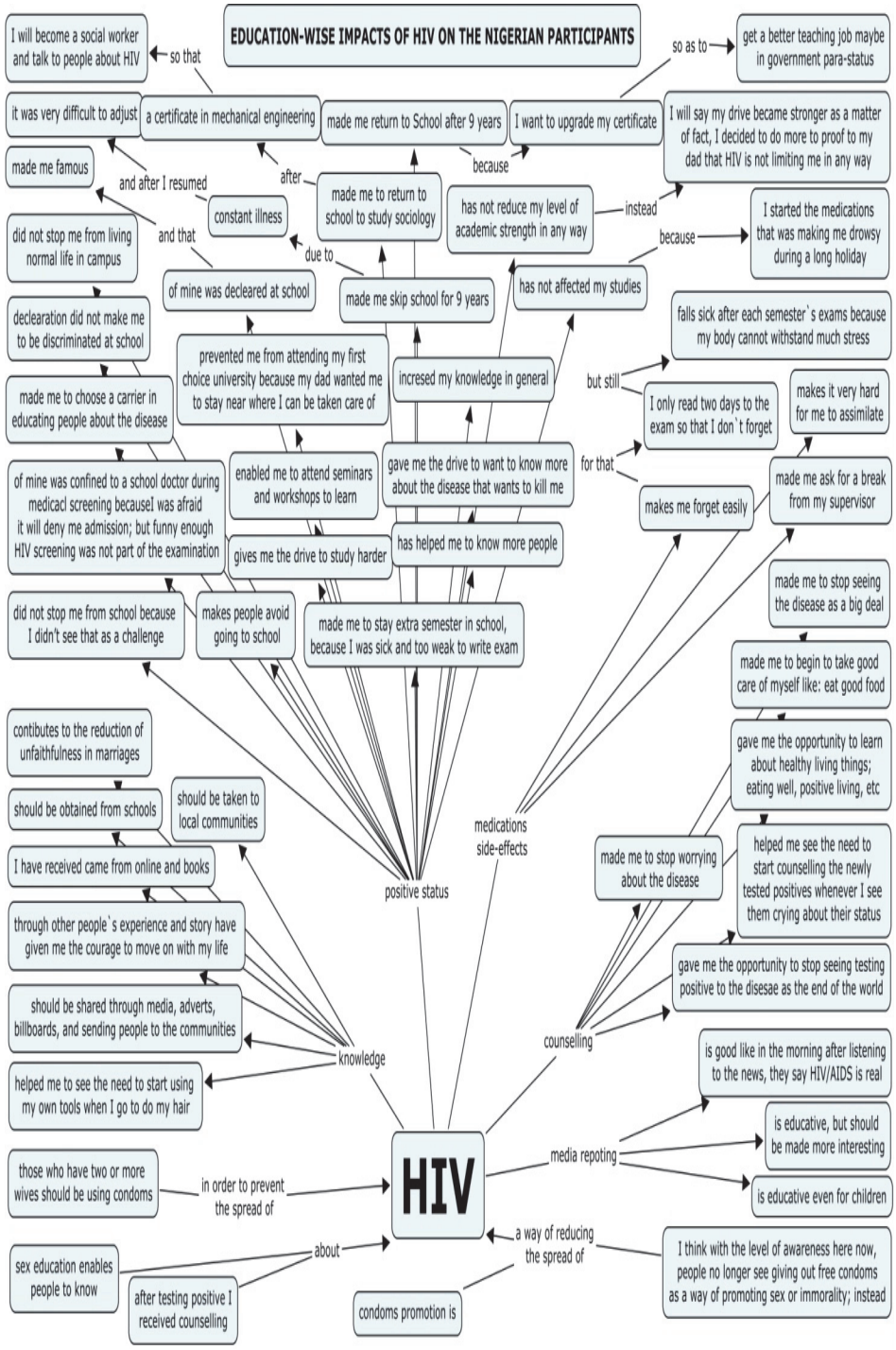


**Figure 23.** Concept Map on the impacts of HIV on the Nigerian participants' education

## 4.6 Impacts on productivity and future goals

So far it has been established that HIV has had positive and negative impacts on participants' health and education, this category looked beyond this two to explore impacts of the disease on participants` productivity and future goals. The analysis has been done through three sub-categories namely: Impacts on work and productivity, Fears and worries, and Hopes despite HIV as shown in figure 24 below. The first sub-category is primarily on the impacts of the disease on participants` productivity, while the other two looked at the disease through their future goals.

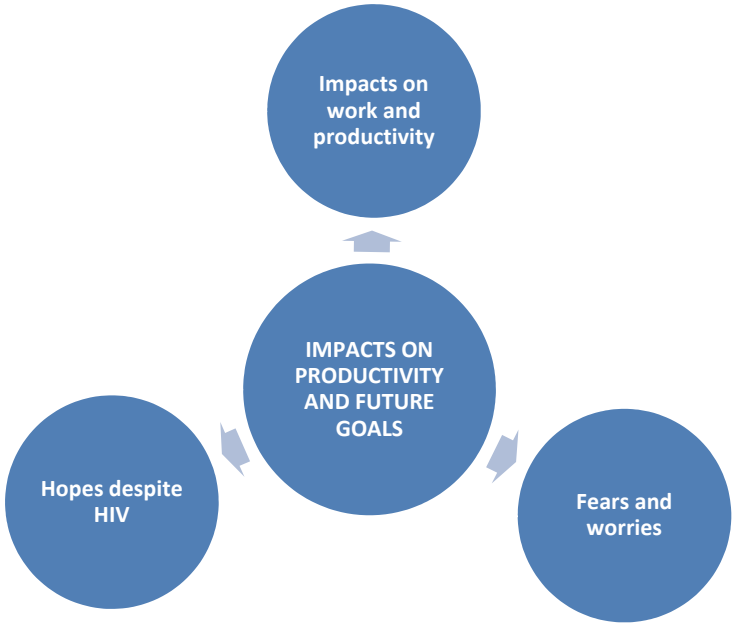


**Figure 24.** The impacts of HIV on productivity and future goals

### 4.6.1 Impacts on work and productivity

Though testing positive to HIV generally appears to mean opportunities lost, it can also mean opportunities gained. This sub-category explored the ways living with HIV had influenced the work and productivity of the Finnish and Nigerian participants in this study. Starting with the positive responses, the themes under which the Finnish participants` conceptions on the impacts of the disease on work and productivity have been explored are: 'medical records in safe hands, no negative effect on productivity, a push to do something with one`s life, reduced capacity to work, sleeping at work, somehow discriminated at workplace'[34], while those of their Nigerian counterparts are: 'holding on to big dreams, going extra miles, a career on educating people about HIV, no barrier to

[34] Here the usual order was not followed because I chose to present the positive side first

career opportunities, less thinking, becoming less productive, limited chances for working, losing one`s job, and economic hardship'.

**Medical records in safe hands/ No barrier to career opportunities:** A Finnish participant believes that her positive status will not affect her work because in Finland, medical records are in safe hands, and will not be released to her boss without her permission.

*I don`t think it would... I think in Finland even if you are working and you have like nurses or doctors at the workplace, I can give them the information but if I don`t say yes they can`t give it to the boss, so I don`t know how it could affect me (sh0485ff).*

This is in contrast with the HIV-positive interviewee in Clarke (2004) who was refused a job by an occupational health doctor because the doctor [who sees it as his responsibility to protect the company`s finances] believes that the HIV-positive applicant may need more sick leaves than usual or retire earlier. Similar to the Finn, two of the Nigerian participants say they do not see HIV as a barrier to their career opportunities. One of them demonstrated her believe that it may not deprive individuals the opportunity of becoming leaders or occupying important positions.

*Living with HIV does not mean, is the end of the world, it does not mean you cannot be in any position; you can be a leader, you can be anything – so living with HIV is nothing (as0481fn).*

While the other believes that as long as she looks healthy, she can work anywhere.

*As far as I am healthy, looking healthy, there is no where I cannot work (aw0071fn).*

**No negative effect on productivity/ Less thinking:** While a Finnish participant claims that the disease has not had any negative impacts on her productivity.

*It hasn't affected my productivity at all (sn9975ff).*

One of her Nigerian counterpart in line with McReynolds (2001) argues that working is important for PLWHA because it distracts them from thinking about the disease which puts one`s mind away from any virus in the body.

*If someone is working and he is doing well, it makes the person less thinkal – let me use that word. In the sense that their minds are occupied, they are working all that time. So it keeps you busy, you don't have to think any virus in your body (ht0484fn).*

**A push to do something with one`s life/ Holding on to big dreams:** For a Finnish participant who became lousy, testing positive to HIV gave her goals, and restored her motivation to do something with her life.

*I think in my case it just affected it positively. It kind of like give me some goals. I kind of like maybe has more goal to do something. Like I explained*

*earlier, it kind of gave me the boost like to do something with my life, and not just to hang around not just doing something. It`s kind of in some way given me some reason with HIV to do things. Even though that after I found out I have been more driven to do stuffs (sh0485ff).*

Then for her Nigerian counterpart, it also mean holding on to big dreams which she encourages others to imitate.

*For me I still want to be one of the best designers in the world, I still want to learn fashion designing, ...you don't say because I have a virus okay let me not be exact what am going to do, whatever profession you do, going to school is not the only thing, whatever profession they want to do they should do it very well (ht0484fn).*

**A career on educating people about HIV:** Since it is of paramount importance for PLWHA to champion giving HIV/AIDS education so that fear and prejudice may decrease, and constant protective behaviour reinforced (Paxton 2002), two of the Nigerian participants see living with HIV as the opportunity to find a career in educating people about HIV/AIDS. One of them who had just concluded her training for such service said she will soon resume the job.

*Fortunately for me, the job that I have is actually to educate people on what HIV is all about, that is why I got a lot of this training last week in Abuja. So the job that I have is actually to educate people, me being the figure head to tell people that HIV is actually not a death sentence after all. It`s actually not a barrier, am going to have a normal job, doing the thing I like to do.... I am opportune to be living with it, when I am able to know actually the problems, but how about those in the rural areas who are not educated or talked to about the whole thing. In matter of weeks to come, I will be going to Osun State to create more awareness (tp0389fn).*

The other began in 2005 to do live media HIV/AIDS education programmes, where she repeatedly educated the public.

*When I volunteered for one organisation, I was a week for their programme, and present their 'AIDS Online', the TV series and a radio programme live. That was my first major appearance that was 2005, and talking about HIV (ht0484fn).*

**Going extra miles:** The same Nigerian participant also sees the disease as a motivation for going extra miles, and doing what people see extraordinary. For instead of seeing the disease as a hindrance to working, she also runs a youth project in addition to her fulltime job.

*I also have a youth project that I do, so I do what people see extraordinary (ht0484fn).*

**Reduced capacity to work/ Becoming less productive:** But contrary to experts` argument that, the earlier a person detects HIV-positive status, the lesser the disease effects on his/her ability to work or study (NordPol 2007); a Finnish participant and her Nigerian counterpart who have lived with the disease for 20

and 13 years respectively believe that the disease has reduced their ability to work. For the Finnish participant, her productivity is affected by tiredness resulting from the disease`s neurological side-effects, but she is still estimated 75% normal and fit to work, and her resilience and past achievements contributes to the cheerfulness which keeps her going.

*The tiredness and neurological side- effects affect my productivity, of course. I have estimated that I am 75% from normal. But used well and wisely, this is enough. At employee´s health care I have told my doctor and they see no implication why I should not continue working. But as I said, times have changed. People have seen me in relatively good health for nearly 20 years now. They saw me give birth to a hiv- negative child, they saw me study, they saw me graduate and now with a steady job (ms9367ff).*

Her Nigerian counterpart, who now works less, said she can no longer do strenuous work so as not to be weighed down.

*Like now I can`t do any strenuous work, I can`t do anything that is very strenuous. I work less now. I don't work as I use to work, because when I work as I use to work before, it will weigh me down, to avoid that I have to reduce my [work] (aw0071fn).*

**Sleeping at work/ Limited chances for working:** Another work related negative effect the disease has had on the same Finnish participant is that it embarrasses her with undue sleeping, even at important meetings.

*When seated, doing nothing I often easily fall asleep, which is embarassing at important meetings (ms9367ff).*

Her Nigerian counterpart said despite her limited chances for working, she still manages to work, and contributes to her family expenses.

*Each day of my life I want to grow higher, that is why I use to, am struggling to still contribute in the family, to see the wellbeing of the family, I did not abandon it for the man alone, even if is hundred naira is something in the family. You know, when as we are positive, if we don't have something that you are doing, giving you money and the load is on one person (a spouse) alone, you know how men, at time, it won`t be very good (aw0071fn).*

**Somehow discriminated at workplace/ Losing one`s job:** Since work related discrimination is perhaps one of the greatest challenges for PLWHA (Clarke 2004), the same Finnish participant again said she had suffered slight discrimination in her second job. However, she remains pleased that her positive status disclosure to her employer`s health care unit was acknowledged as a proof of her honesty.

*At work I suffered surprisingly little. I have had two jobs, where they knew about my status. In the firts one my boss was ok about it, in the second one I was discriminated for this and other reasons. There are not many hiv- positive practising. My employee´s health care unit said that I was the firts one there. They thanked me for being honest. Together we follow my ability to work under such streass wery closely (ms9367ff).*

Then her Nigerian counterpart who had live with the disease for about 13 years again said she left her job as a private school teacher because she was refused a monthly day off for medical check-ups.

*I called the woman I told her please every last Wednesday or Thursday I will be going to the hospital for medical check-up, I didn't tell her my status. The husband of the woman accepted so the following day I came to work. She came to me, 'madam, I have thought about this your medical check-up, I don't think it will work, unless you will leave it oh', immediately I said madam, I cannot compromise work with my health (aw0071fn).*

**Economic hardship:** Koopman et al. (2000) revealed that personal income has effect on the level of one`s HIV stress. As such, the stress of the same Nigerian participant who forfeited her teaching job had increased due to economic hardships.

*Is very difficult for average Nigerian talkless of somebody. Last week I travelled, I when to solicited for my children school fees ... Things are not as it was for my husband, so one wanted to take WAEC, because he is owing they did not allow him to take mock, and the whole thing was on me – thinking, God helped me I did not break down (aw0071fn).*

### 4.6.2 Summary of impacts on work and productivity

In this sub-category a total of 17 themes (7 and 10 from the Finnish and the Nigerian participants respectively) emerged on the impacts of HIV on work and productivity. They reveal that living with HIV/AIDS improves commitment to the work. To a Finnish participant there is no fear that being HIV-positive will not affect her work because her medical records are in safe hands, and another believes that it helped her to recover from lousiness after she lost focus of what to do with her life. Similarly, their Nigerian counterpart sees it as a push to hold on to her big dreams. Besides it also means to her a kick to do extraordinary things. Two other Nigerian participants see living with the disease as an opportunity to find a career in educating people about HIV/AIDS. Another encourages others not to see HIV as a barrier to their becoming leaders or occupying respectable positions in the society. Then while a Finnish participant claimed that the disease has not affected her productivity negatively, her Nigerian counterpart recognises working as an opportunity for taking one`s mind away from thinking about a deadly virus in the body.

But a Finnish participant and her Nigerian counterpart who have lived with the disease for 20 and 13 years respectively said the disease has reduced their working capacity. The Finn said it embarrasses her with frequent sleeping even at important meetings, and the Nigerian said it has reduced her chances of finding work. The Finn also said she had received some soft discrimination at her workplace, and the Nigerian said it made her to lose a teaching job, and the economic hardship resulting from that had increased her stress. So except for the Finnish participant and her Nigerian counterpart who have lived with the disease for 20 and 13 years respectively, the disease has had no negative im-

pacts on the participants` productivity, instead they experienced positive ones. Nevertheless, the Nigerians participants seem slightly more positive about their condition, which may have contributed to why two of them decided to choose a career in giving public health education on HIV/AIDS.

For further insight, concept maps in figures 26 and 27 in pages 179 and 180 separately mapped out the overall impacts of HIV on productivity and future goals as experienced by the Finnish and Nigerian participants, and table 28 in appendix VI shows the comparison between the Finnish and Nigerian participants` conceptions on the impacts of HIV on work and productivity, and the comparison was backed with findings from earlier studies. The next sub-category explored the impacts of HIV on fears and worries.

### 4.6.3 Fears and worries

Many of the PLWHA are often gripped by fear due to the assumption that their opportunities for a bright future have been destroyed by the disease (Gachuhi 1999), and as a result they are constantly troubled. This sub-category looks into the fears and worries of the Finnish and the Nigerian participant. The themes under which the Finnish participants conceptions were explored are: 'worries about twelve pills a day, worries about coping with side-effects, standing out, fear that people will find out, fears relating to being hired, worry about disclosing to a daughter someday, fear that a social worker will not keep to non-disclosure obligation, fear of being rejected, distorted future, and no cure in sight'. While those of the Nigerian participants are: 'fear of taking pills for life, and afraid of nothing'.

**Worries about twelve pills a day/ Fear of taking pills for life:** Being on ARV often requires taking more than a pill per day, and for a life time. As such, a Finnish participant who who`s daily pills has risen to 12 is deeply worried about how long her body is going to withstand it.

*Deep down I have wondered how long is my body going to support all these drugs. 12 pills a day I am taking (ms9367ff).*

Two of her Nigerian counterparts acknowledging similar stress are worried about taking pills for life. While one claims it scares people away.

*ARV is actually the thing for a lifetime, the medication you are to take for a lifetime, so that in a way scare people (tp0389fn).*

To other, though it is somehow, she plans to continue to adhere because it is her life.

*Take drugs everyday is somehow, but is my life, I have to take it (as0481fn).*

**Worries about coping with side-effects:** Furthermore, the same Finnish participant who had also lived with the disease for about two decades is as well worried that her body might not be able to cope with the heavy side-effects of her medications; for her body is already being disfigured, nevertheless she still has hope.

*Due to heavy side effects of the drugs my body might not be able to cope just as long. But then again it might (ms9367ff).*

**Standing out:** According to the UNAIDS/WHO (2008) epidemiological fact sheet, the prevalence of HIV/AIDS in Finland is relatively low (about 2600). Ideally such a limited number of PLWHA in a population of over five million calls for celebration, but a Finnish participant claims that it actually added to their woes because it limits their social interactions unlike in the UK, and the limited number is also responsible for the gross HIV/AIDS ignorance among Finns, and it also makes it easier for them to be spotted out in a small country like Finland and tagged - immoral.

*I think in Finland is so difficult, the number in Finland is not so much like in UK, there is not so much knowledge, people don`t have so much information, people don`t know someone with HIV, so I think the view here is like drugs, people who use needles ...this country is still so small people will recognise you (sh0485ff).*

**Fear that people will find out:** Another Finnish participant is afraid that people will find out someday and somehow that she is HIV-positive which may compelled her to defend why she is occupying a given public position despite her positive status.

*It has brought a lot of you know fear that people will find out. I have this worry that somehow someday people somewhere, people will find out about this disease I will be in a situation where I have to defend myself. Like defend myself, like defend my right to be in that thing – position I mean (sn9975ff).*

**Fears relating to being hired:** Besides the fear about occupying a public position, the above Finnish participant is also afraid that, the person who hires her may find out about her positive status too.

*I think that`s the – I think maybe if in some way someone will hiring me, will find out about it in some way (sn9975ff).*

**Worry about disclosing to a daughter someday:** Though the time is still far from now, but realising that she will someday disclose to her less than two years old daughter, the same Finnish participant is also worried about what her reaction will be.

*My daughter is a year and half, sometime I wonder what would she say, what would she think one day when I tell her about this (sn9975ff).*

**Fear that a social worker will not keep to non-disclosure obligation:** Lack of confidentiality often prevent HIV-positive individuals from seeking support. Even some of the PLWHA have problem trusting one another (Issiaka et al. 2001). Similarly, one of the Finnish participants is afraid that a colleague in her workplace who is also a social worker and knows about her positive status may not keep to the non-disclosure obligation required of every social worker. This is despite the social worker`s assurances not to.

*At my recent job one of my collegues is a social worker, who knew me and my life´s history, my illness etc. from the time I was a client at the social services. When I realized that she was going to be my collegue, I went to her saying that I trust her to keep my secrets, She said that she is under non- disclosure obligation and that I should not worry. But I know how the collegues gossip about customers and work mates (ms9367ff).*

**Fear of being rejected:** Although no one wants to be isolated, solitude remains the presumed major problem for PLWHA. According to NordPol (2007), 59% of respondents believe they are alone despite the fact that they prefer people`s company. As such, one of the Finnish participants is very much afraid that, people finding out about her positive status will lead to her being rejected.

*This disease is something I think or am afraid is probably just my fright that says that if people find out they will reject me, is probably not true, I know that you know intelligent people most likely they won`t (sn9975ff).*

**Distorted future:** HIV/AIDS has strong impacts on individuals` ability to plan for the future (Clarke 2004). As such, a Finnish participant said each time she looks at her life through HIV, the image she sees makes her feel that she is not going to get the best out of life.

*Probably still, I have sometimes think that, when I look at life through the disease I think that maybe it can`t offer me like this full life (sn9975ff).*

**No cure in sight:** Unfortunately, there is still no known universally recognised cure for HIV/AIDS, and that calls for worry. So while a Finnish participant believes that it is going to take a very long time before a cure will be found.

*I think it will take a long long long time before you find a way to get rid of, to be cured totally of the disease, probably even longer before you get vaccination for it (sn9975ff).*

Another does not see it as something to be hoped for in the near future

*...but not in the near future, I don`t think so (sh0485ff).*

**Afraid of nothing:** Then contrary to the above fears, three out of the four Nigerian participants say they have nothing to be worried about. One of them said the biggest price she can pay for being HIV-positive is that some people may avoid her, which to her does not call for worries.

*Nothing to, why would I fear? May be at worst they won`t want to talk to me. Do I even want to make someone a friend? Must I make friend with people? I make friend with people that love me. I will have children like normal person, since there is solution, there is nothing to worry about (as0481fn).*

Another said the disease does not worry her because she has seen the HIV-positive people marry those who are negative and they gave birth to HIV-negative children.

*There is nothing to be afraid of because now am so sure I have seen people, positive married to negative spouse, and they have negative children (tp0389fn).*

Then the third is not worried because she knows what her rights are, and that gives her the privilege to sue an employer if she is sacked because of her positive status.

*I don't even have fear because I know my right. If I get an employment now, and the person sack me because am [positive], if it happen the person sack me, I will sue him (aw0071fn).*

### 4.6.4 Summary on fears and worries

In this sub-category a total of 12 themes (10 and 2 from the Finnish and the Nigerian participants respectively) emerged on the participants` fears and worries. They show that the participants are concerned mostly about the social challenges before them due to their HIV-positive status. But most of the concerns were exhibited by the Finnish participants. For beside the two Nigerian participants who expressed their concern about taking pills for a lifetime, every other concern were expressed by the Finnish participants as shown in figure 25 below. Their fears and worries include; the feelings that one can easily be spotted out because the PLWHA in Finland are few, one`s employer may find out someday, and the individual may be asked to defend why she is occupying a public post despite her positive status which may lead to her being publicly rejected. There was also expressed the fear of what a daughter`s reactions may be when her mother will disclose to her. Another Finnish participant is afraid that her colleague who is also a social worker may not be able to uphold the non-disclosure obligation which social workers are bound to keep. She is also worried about how long her body will be able to withstand 12 pills every day, coupled with the side-effects the medications had brought upon her. There was also expressed the worry that the disease has taken away the opportunity of getting the best out of life, and concern that there may be no cure in the near future.

But contrary to the above 10 fears and worries exhibited by the Finnish participants, three of the Nigerian participants said they are afraid of anything whatsoever because the disease does not prevent them from marrying HIV-negative spouses, give birth to HIV-negative children, and also because the law protects and gives them the right to sue an employer who sacks an employee solely because of his/ her HIV-positive status.

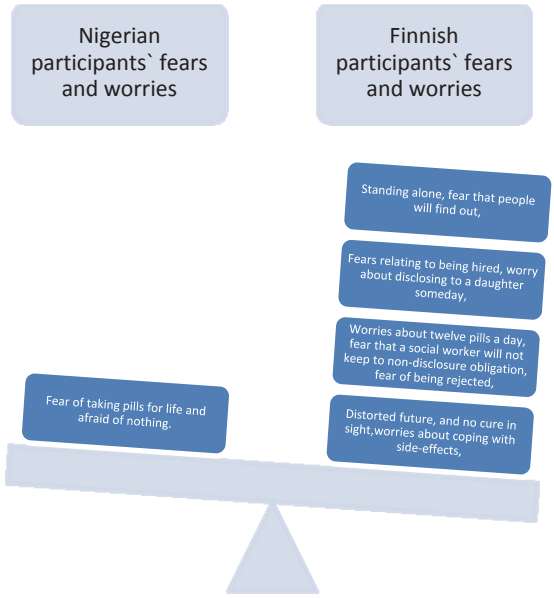


**Figure 25.** The difference in the Finnish and Nigerian participants` fears and worries

It seems surprising that the Nigerians who lack most basic needs nurse little or no fear about their positive status while as the Finn who have at their reach almost everything they want are the ones worried and gripped with fear. Perhaps it has something to do with each groups` social environment, or perhaps the Finns were more vocal. For further insight, concept maps in figures 26 and 27 in pages 179 and 180 separately mapped out the overall impacts of HIV on productivity and future goals as experienced by the Finnish and Nigerian participants, and table 29 in appendix VI shows the comparison between the Finnish and Nigerian participants` expression of HIV related fears and worries, and the comparison was backed with findings from earlier studies. The next subcategory explored the hopes in participants despite their HIV-positive status.

### 4.6.5 Hopes despite HIV

In what is referred to by some as ‘Lazarus syndrome’ (uncertain life after certain death), the image of PLWHA which use to be portrayed as individuals wasting away, frail, dying or on the verge of death has almost completely changed, and the shift from dying of to living with is rekindling hope (Kelly 2007) to many of the PLWHA. While hope can either be global or personal (Lowth, Yallop, Reid and Fitzgerald 1999), it has proven to be an important resource for responding positively to HIV/AIDS (Kelly 2007). The few hopes which the participants of this study expressed are described in this sub-category. From the Finnish participants, hope themes are: ‘hope for fulfilled life, hope for better drugs and cure, and hope of medications for all’. While those of the Nigerians are: ‘hope for a bright future and hope for cure’.

**Hope for fulfilled life/ Hope for a bright future:** A Finnish participant said that while she is presently enjoying her studies, she has the hope that her dream of living a fulfilled life which includes working, becoming financially independent, and finding a husband will be realised someday.

*Good life, happy life someday. I enjoy my study; I think I will enjoy my work someday. I have a beautiful daughter, am quite sure someday I will have husband or you know someone to share this life with ...I think I would be independent financial independent (sn9975ff).*

Two of her Nigerian counterparts also have the hope for bright future. While one said the motivation to continue to pursue her academic career gives her hope for a bright future.

*Still having the drive to pursue my career gives me hope (tp0389fn).*

The other totally relies on God for a bright future which includes seeing her grandchildren.

*My future is very bright, and I long to see my children`s children if God permits because I know He is the only one that has the final say (aw0071fn).*

**Hope for better drugs and cure/ Hope for cure:** Two of the Finnish participants expressed their hope for better HIV medications and possibly a cure. While one of the two who does not believe that she will dye of the disease said her hope is built on the fact that in the past 10 years HIV medications have been getting better, as such she believes that in the next 10 to 15 years the medications will get even better, and God willing a cure may be found.

*Especially because in 10 years the drugs, everything have developed so much, so God knows what in 10 or 15 years in the future, everyone working to find better drugs maybe cure (sh0485ff).*

The other in expressing her hope said the side-effects will hopefully reduce, life expectancy increased, and a cure like in TB found.

*Even better drugs will come along. Life expectancy will be longer and hopefully side effects will be lighter ...I have a hunch, the treatment will come up from nature or animals, just as it did with tuberculosis (ms9367ff).*

Two of the Nigerian participants also expressed their hope for a cure. One of them banking on the fact that initially there was no medication for HIV and now it has advanced said she is sure that someday soon there will be a cure for the disease.

*I know one day it will go! It will surely go, the drug that will clear it away will soon come, so why would I need to worry myself? That is my believe. Formerly HIV did not have any drug, initially, HIV did not have any drug, but I know very soon they will find a cure drug for it.* We know very soon there will be a solution. I know God has solution for everything. *I know very soon there will be a way to it, there will be a solution, there will be a way out, there will be a drug that will clear it totally. Nothing in this life there is*

*no solution, there is solution for everything only death that does not have solution (as0481fn).*

Then the other who strongly has the hope that the cure will come someday is praying that God will keep her alive till then.

*In the future I know the cure will come, and that is what we are praying for God to keep us alive let us experience the cure (aw0071fn).*

**Hope of medications for all:** HIV medications are believed to have contributed greatly to improving the work capacity of many among the PLWHA, and also decreased their absenteeism from work (Beard, Feeley and Rosen 2009). So while a Finnish participant is not pleased that the medications are not yet available for all, she has the hope that someday soon they will be at the reach of all who need them.

*It will be possible one day for all the HIV people to get medication (sn9975ff).*

### 4.6.6 Summary on hopes despite HIV

In this sub-category a total of 5 themes (3 and 2 from the Finnish and the Nigerian participants respectively) emerged on hopes despite HIV. They revealed that despite all the devastating impacts of HIV, the Finnish and Nigerian participants are still very resilience. The participants expressed hope for fulfilled life and bright future. They have strong optimism that HIV medications will get better, and someday soon a cure for the disease will be discovered. But meanwhile they are looking forward to the realisation of fair distribution of available medications.

For further insight, concept maps in figures 26 and 27 below separately mapped out the overall impacts of HIV on productivity and future goals as experienced by the Finnish and Nigerian participants, and table 30 in appendix VI shows the comparison between the Finnish and Nigerian participants` expression of hopes despite HIV, and the comparison was backed with findings from earlier studies. This is the end of category six on the impacts of HIV on productivity and future goals (consisting of 4 sub-categories and 34 themes – 20 and 14 on the Finnish and the Nigerian participants` conceptions); the next category explored the transformations that have been made in participants due to their new identity.

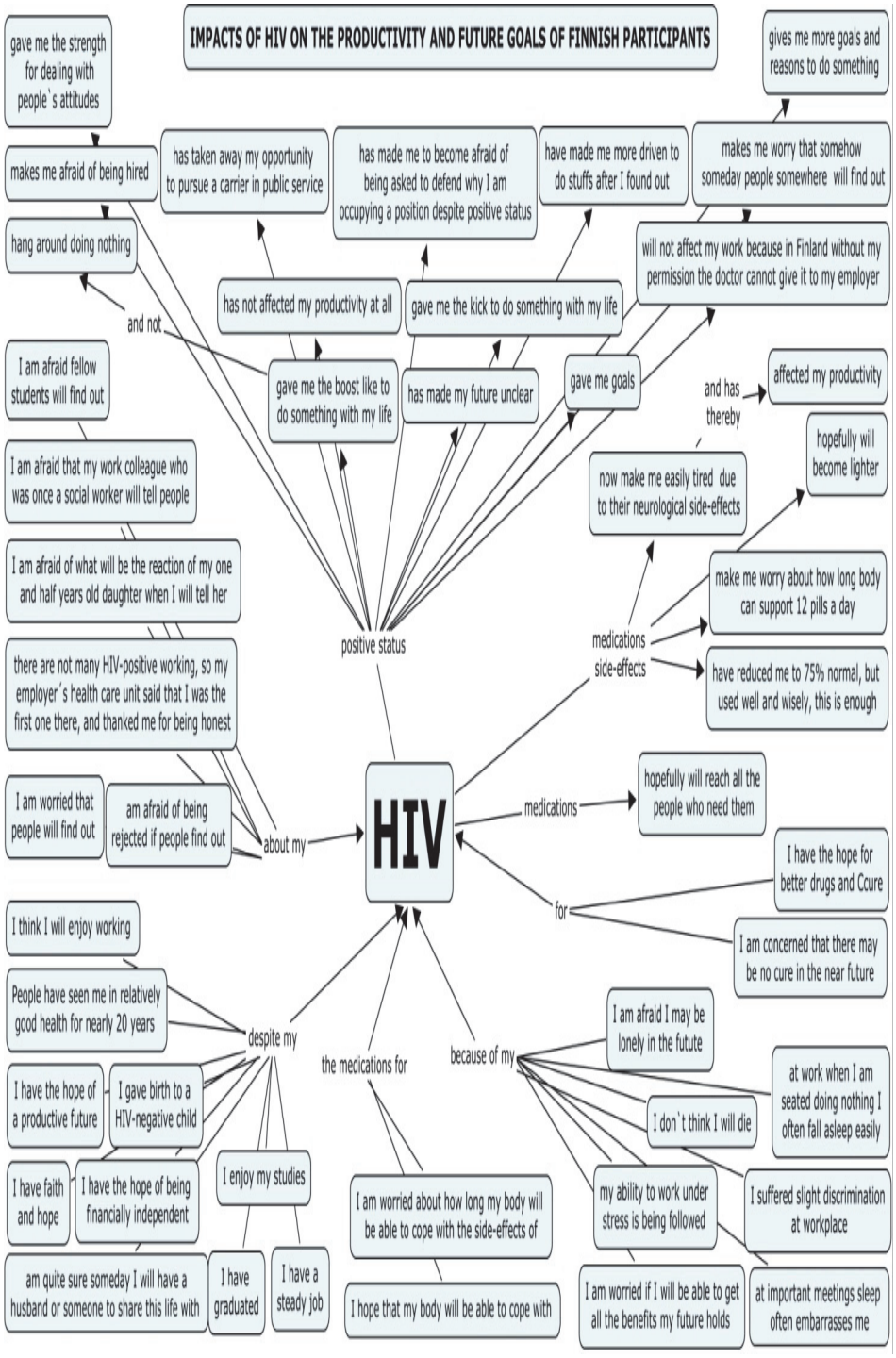


**Figure 26.** Concept Map on the impacts of HIV on Nigerian participants` productivity and goals

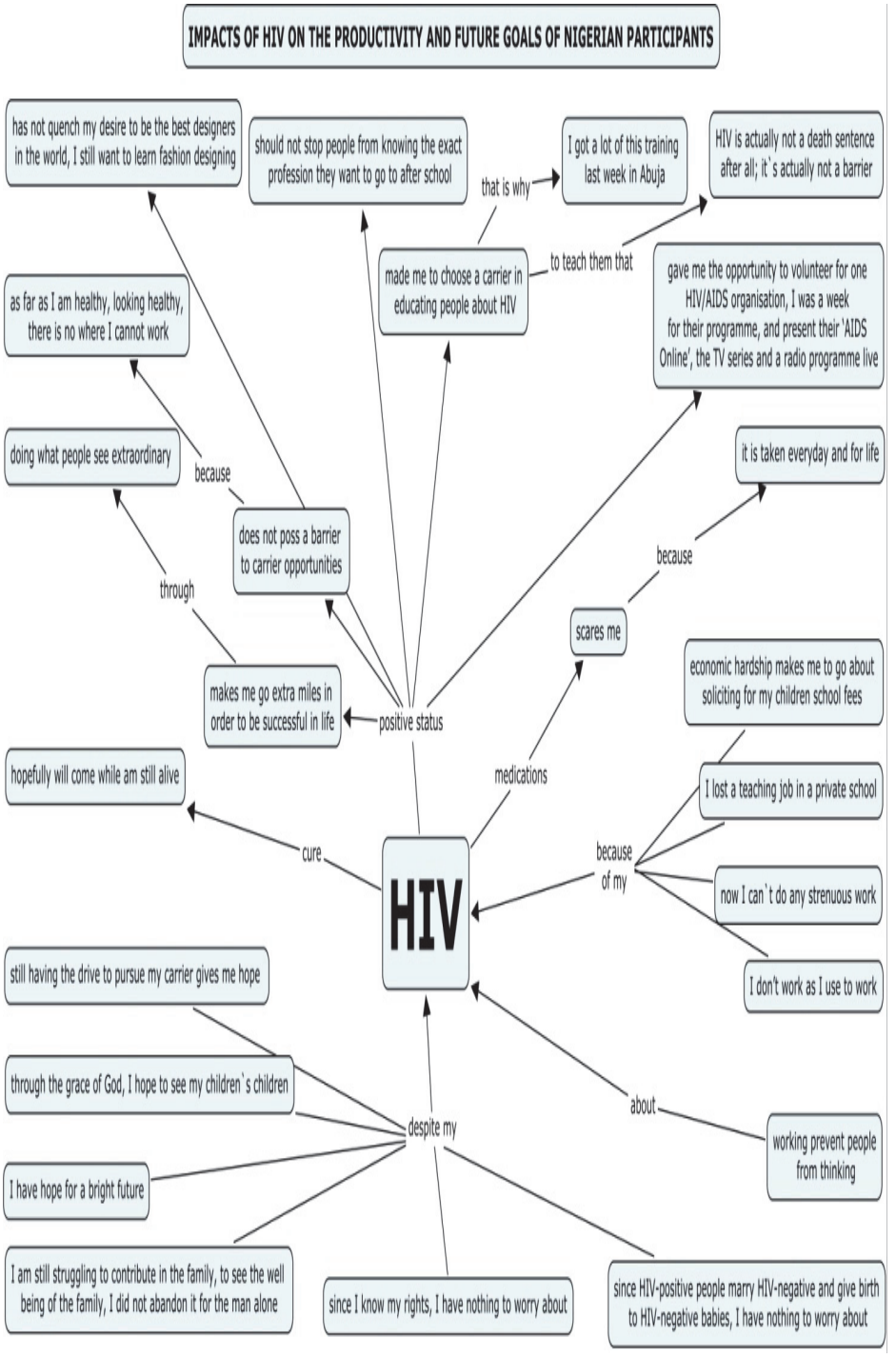


**Figure 27.** Concept Map on the impacts of HIV on Nigerian participants` productivity and goals

## 4.7 Transformations after testing HIV-positive

As held by many, if there is one constant thing in life; it is change! As such, for an individual to remain the same after testing positive to HIV seems next to impossibility which is why either consciously or unconsciously after the diagnosis, individuals begin to behave differently due to changes in their self-perception. For many individuals, completely new lifestyles are formed in order to adapt to the new identity and/ or check the progression of the disease which in return prevents their health from deteriorating further, or their life unnecessarily shortened. This category examined the HIV induced changes in the participants through two sub-categories namely: 'Transformations due to new self-perceptions and HIV related reformed lifestyles' as shown with a symbol of revolving gears in figure 28 below.

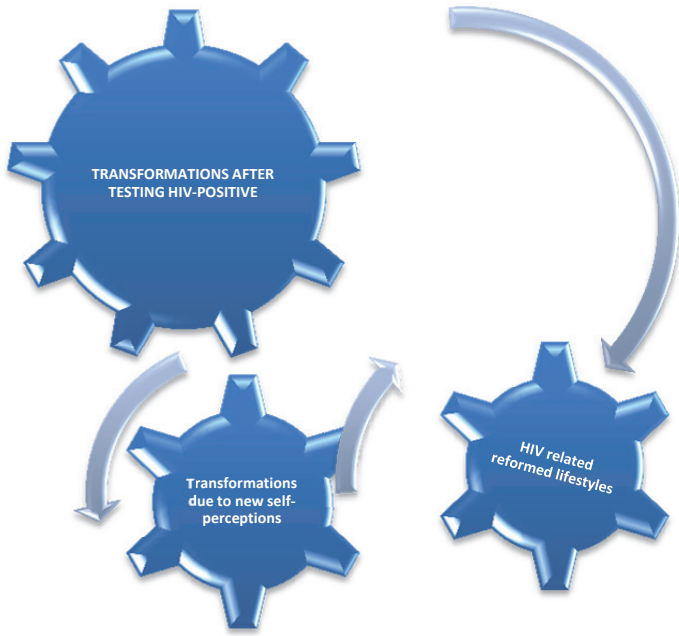


**Figure 28.** Transformations in participants after testing HIV-positive

### 4.7.1 Transformations due to new self-perceptions

For the fact that changes are inevitably bound to occur after testing positive to HIV/AIDS, this sub-category from general perspective explored some of the major changes which occurred in the Finnish and Nigerian participants after testing positive to HIV. The themes under which the experiences of the Finnish participants were explored are: 'new perspective to life, realising that life has no duplicate, sustainable living, transformation into a better person, and a warrior

princess'. While those of the Nigerian participants are: 'new way of seeing things, attention to health, becoming a better cook, transformation into a better person, voluntarily joining of anti-aids club, additional privilege, planning one`s life, time consciousness, and little or no change'.

**New perspective to life/ New way of seeing things:** A Finnish participant acknowledged that death is inevitable, nevertheless, to live with a constant reminder of its inevitability puts new perspective to one`s life.

*Obviously someone die at some point, but when you get some reminder that you are going to die at some point, then it can like put new perspective (sh0485ff).*

Her Nigerian counterpart said living with HIV has completely changed her for the better.

*It has changed for the better (my way of seeing things), it has changed completely (aw0071fn).*

**Realising that life has no duplicate/ Attention to health:** Many generally behave as though their life have no value, but once life threatening incident occurs, life`s value quickly pups up, and their minds become refreshed of it. So in most cases, once an individual tests positive to HIV/AIDS, he/ she will suddenly improve self-care in order to control the progression of the disease (Anderson and Spencer 2002). As such, a Finnish participant said she has realised that she has just one life which cannot be duplicated, and for that reason she need to live it well.

*I realised that I only have this one life that I need to live, and I need to live it as good as I can (sn9975ff).*

But testing HIV-positive drew the attention of her Nigerian counterpart to caring for her health which includes preventing mosquito bite because malaria kills even faster than HIV.

*By testing positive drew my attention to my health, I stay healthy, I care about where I sleep not expose myself to mosquito bite, because malaria is a killer disease – it kill faster than HIV (tp0389fn).*

**Sustainable living/ Becoming a better cook:** Testing positive to HIV made a Finnish participant to realise that overstretching one`s self in search for wealth is unwise, so she has decided to take life cool.

*I know that I had to take it more easy, I want to because in the same time also I realise that work isn`t my life or money or nothing like that, but I always, little hippy, so I think even without it I think I would more chill, not so! I don`t think about productivity so much, I just hope that I can find a job that help to save the world in some way, but am not really interested about money and everything like how the world work, so! (sh0485ff).*

Furthermore, it is unfortunate that with fast food joints all around us today, many carelessly and constantly eat junks at the detriment of their health. So a

Nigerian participant who once belonged to such group said, she is now a changed person courtesy of testing positive to HIV. According to her narrative, HIV has made her a better cook, and unlike before, she no longer feed on junks because living with the disease enabled her to know the need for eating healthy food.

*HIV made me a better cook, HIV made me a better cook, because I use to, am like I feed on junk, bread & tea, bread & sardine, but when I tested positive to HIV, I got to know the need to eat well, then I learnt to cook, and I improved. I cook my meal, I cook myself and I enjoy doing it (tp0389fn).*

Similarly, in NordPol (2007), the respondents said they began to eat healthier after testing positive to HIV.

**Transformation into a better person:** In Anderson and Spencer (2002, 1348) one participant who thinks that there are positive side to having AIDS said, *"If I didn't have AIDS, I'd probably still be out there drinking, drugging, and hurting people. I turned my life around. I gave myself over to the Lord and Jesus Christ."* In like manner, a Finnish participant and a Nigerian counterpart say living with the disease had made them better individuals. The Finn said it made her the better person she wouldn't have been without it; for instance, she no longer judge people easily.

*I think maybe it has made me you know a little bit better person than I will be without it, because maybe I don`t judge other people easily (sn9975ff).*

The Nigerian said, testing positive to HIV has benefited her in many ways which includes a transformation from wayward lifestyles.

*Things that are good in testing positive to HIV are many. If you have been living a wayward life, it will change. If emm okay, if you are someone that always quarrel so much, it will change. And the way you see things will change (aw0071fn).*

**A warrior princess/ Voluntarily joining of anti-AIDS club:** In Anderson and Spencer (2002, 1346) where a participant said: *"I'm a fighter and I'm never going to give up until they come up with a cure for this"*. Similarly, the Finnish participant who had struggled with the disease for about twenty year said, living with HIV makes her to see herself as a warrior princess.

*As a warrior princess (ms9367ff).*

Then her Nigerian counterpart said, that the anti-AIDS club in her school which she once thought she has no business with, she voluntarily joined after testing positive to HIV.

*I see them I was like I don't have any business let me just face my study and just get out of the school. When I knew my status, I have to then voluntarily join the anti-AIDS club (ht0484fn).*

**Additional privilege:** Two of the Nigerian participants said living with HIV gave them additional privileges. One of the two who is now working with a HIV/AIDS organisation said the disease gave her the opportunity to enter hard-

to-reach places, and meet highly placed individuals whom she would not have had access to ordinarily.

*Am a kind of privileged meeting with some people in high places. Imagine meeting with the MD (Managing Director) of NTA (National Television of Nigeria), MD of Chevron, ordinarily I wouldn't have even if I am working, in a good day I wouldn't walk up to the MD`s office and say I want to see him. So for me that is an advantage (ht0484fn).*

The other claims that the disease opened doors of opportunities for her, and without it she will not be where she is today. She also said that she now lacks nothing because her dad who will not want to see her depressed has been showering her with funds even to the point that he recently sponsored her trip abroad which ordinarily he would not have done.

*I will say being HIV positive opened doors of opportunities. I even wonder within me that if I had not tested positive, I won`t be where I am. Okay for instance, my dad gives me extra attention in the sense that I do not lack anything, I do not lack anything. Last year I was opportune to travel to (name of the country withheld), and am very very sure he wouldn't have sponsored that trip. But because I said please this will make me happy, he accepted. So HIV has not limited me in any way (tp0389fn).*

**Planning one`s life:** Someone once said that the difference between the rich and the poor is 'plan'. Unfortunately many are not successful in life because they lack this one essential quality – planning! But to a Nigerian participant, living with HIV enabled her to start doing so.

*There is many positive things about it. You will then need to plan your life if you are the one that don't use to plan your life before, you start planning for it. If you have children you will start planning for those children in case if anything happen the children will be comfortable where ever they are. It helps you to plan your life (aw0071fn).*

**Time consciousness:** The phrase 'African time' is often used in Nigerian to connote the inability of an individual to keep to appointment, or the inability of a group to start a programme at the exact time due to late arrival of the attendants. So, while in Finland wall clocks in both public and private places are scarce, Finns remain very time conscious. But in some Nigerian households you may find up to four or more wall clocks hanging in the living room alone, yet members of many households still arrive late at programmes due to their lack of time consciousness. But contrary to this trend, a Nigerian participant said living with HIV has changed her, and now she is always time conscious and punctual due to her medications` regular schedule.

*Like now, am always time conscious, any place I am now, even without my time, if that time get to time to take my drug, I will feel somehow in my body, then I will remember that I have to take my this thing [pills]. And now I always keep to time, whatever am doing, I keep to time (aw0071fn).*

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**Little or no change**: But unlike others who have observed significant changes in themselves, a Nigerian participant said living with the disease has caused no change in her except that she is on HIV medications.

*It never changed anything, and it will never, the only thing that has changed in my life is the drug (as0481fn).*

### 4.7.2 Summary of transformations due to new self-perceptions

In this sub-category a total of 14 themes (5 and 9 from the Finnish and the Nigerian participants respectively) emerged showing the transformations made in the participants due to their new self-perceptions. They reveal that significant changes occurred in the life of the participants after their HIV-positive diagnosis. For while living with a constant reminder of inevitable death brought new perspective to the life of a Finnish participant, it changed a Nigerian participant's way of seeing things for the better. Again while a Finnish participant like many others did not value her life the way she should, after testing positive to HIV, she realised that life has no duplicate and should be well lived. Then her Nigerian counterpart said testing positive made her to begin to pay closer attention to her health. The participants also claimed that said the disease has transformed them into better persons.

A Nigerian participant who once thought that she will have nothing to do with the anti-AIDS club in her school voluntarily joined it after she tested positive. Another Nigerian participant said living with the disease has given her additional privilege to meet with highly placed individuals whom ordinarily she might never have had access to. Yet another Nigerian said among many other advantages, living with HIV helped her to start planning her life which she was not doing earlier. She also claimed that through taking her medications regularly, she has adapted to time conscious lifestyle. Still another Nigerian participant said testing positive to the disease has made her a better cook, and as a result she no longer eats junks like before. A Finnish participant said haven struggled with the disease and its effects for a long time and prevailed, she is now a warrior princess. But sounding different from every other participant, a Nigerian said besides taking HIV medications, the disease has made no change in her.

From these responses, it seems many positive changes have taken place in the life of the participants in both group, but the Nigerians seem slightly more vocal about theirs. For further insight, concept maps in figures 29 and 30 in pages 192 and 193 separately mapped out the transformations that have taken place in the Finnish and Nigerian participants due to their HIV-positive status, and table 31 in appendix VII shows the comparison between the Finnish and Nigerian participants` expression of new self-perception induced transformations, and the comparison was backed with findings from earlier studies.. The next sub-category explored the participants` reformed lifestyles as a result of their HIV-positive status.

### 4.7.3 HIV-related reformed lifestyles

As in diagnosing positive to other chronic diseases, once a person tests positive to HIV/AIDS, the irreversible is already done, and though finding out how it came, identifying who is to be blamed, and so forth may serve some purposes, the most important thing for the individual remains looking for the best way forward; the most common of which is using medications. But in addition to HIV medications, PLWHA often need counselling, psychosocial support, access to good nutrition, safe water, basic hygiene, and so forth in order to maintain or improve their quality of life (WHO 2010b).This sub-category examines the conceptualised best ways forward beside medications which the Finnish and Nigerian participants have adapted to, in order to mitigate the impacts of the disease, better their chances of living healthfully, and prolong their lives. The themes under which the experiences of the Finnish participants were explored are: 'a wake-up call, positive living, controlling appetite, less stress, good hygiene, the biggest reason not to do drugs again, strict temperance, balanced diet, remaining a vegetarian, and outdoor exercise '. While the Nigerian participants` themes are: 'changing old habits, healthful living, carefulness in choosing what to eat, less stress, an end to sharing shape objects, avoidance of opportunistic infections, and being in a mosquito free environment'.

**A wake-up call/ Changing old habits:** Though it is often difficult to refrain from old habits (Kalu 2010), living with HIV/AIDS goes a long way in motivating individuals to do so. As such, a Finnish participant sees HIV as a wake-up call which has helped her to begin to live healthfully despite the challenges with making adjustments. She started adjusting because living with HIV gives her the feeling that her body is now frailer than that of normal individuals.

> *I try to eat healthy, and I stopped smoking cigarette, and I try to exercise but well try, meanwhile my schedule at the moment is so busy, yeah obviously I have to think what do, I do for my body because is more frail than normal people, this is not easy but I have to be more careful (sh0485ff).*

Furthermore, in order to reduce the impacts of HIV, three of the Nigerian participants say they have retraced their steps from some of their old lifestyles. One of them said, unlike before she now takes large amount of fruits and vegetables every day.

> *...and now I eat fruits more than before, I can`t go a day without fruit, and I eat more of vegetable (tp0389fn).*

Another said she no longer takes soft drinks, and has started eating beans far before bedtime to avoid indigestion related problems. She also claimed that she had made many other changes.

> *Like mineral (soft drink), I notice if I take mineral, I will start purging. I have stopped it completely. I noticed beans, if I don't eat beans early sometime, I find it difficult to sleep, the thing will not digest very well, then I stopped that. You know many other things (aw0071fn).*

Then the third advocates that people should avoid being negatively shaped by others, but instead join her in following the healthy lifestyle of drinking enough water, eat balanced diet, take fruits, and so forth.

*People should exercise, eating more balanced diet, emm taking enough water, taking fruits, for me that is how I live. Then having a good fresher life, let me use that word in the sense that most of us are at the habit of people can dictate for us (ht0484fn).*

**Positive living/ Healthful living:** Furthermore, the participants mitigate the impacts of HIV through positive and healthful living (BBC June 2006, Yle June 2012a). A Finnish participant said once she realised that the disease is not that deadly, she began to live healthfully, and now she does not smoke cigarette, drink alcohol, or even party, instead she is now into different kinds of sports, eats healthy diets, rests well, keeps her spirit high, and goes to the theatre.

*I take more care of my health now that I know it is not a mortal disease... I don't smoke, drink or party. I do sports and try to eat and sleep well. I keep my spirits high… Swimming, gym, cycling, aerobics, pilates and healthier diet. Going to theatre. Resting…. (ms9367ff).*

Then two of her Nigerian counterparts claimed that they have also started to live healthfully. While one claims that health-wise, she now does things she never did:

*I eat fruits now before I don't like fruits. I don't like taking a lot of water, I do that now. I don't like exercising or walking too long, I do that now. That is the only thing, all other things my life still remain the same (ht0484fn).*

The other simply claims now she lives relaxed life.

*Relax! (tp0389fn).*

These new lifestyles are in agreement with FAO (2002) encouragements that PLWHA should take extra rest, stress less, keep positive attitude, take light exercise, seek counselling, accept help, quit smoking, avoid non-prescribed drugs, and refrain from alcohol which apart from being harmful to health, influences unprotected sex.

**Controlling appetite/ Carefulness in choosing what to eat:** Loose eating and drinking couple with HIV/AIDS worsen health conditions; this is probably the reason why in NordPol (2007), respondents have reduced their alcohol consumption. Similarly, a Finnish participant who has been trying to eat healthfully said as difficult as controlling her appetite for sweet things may be, she has been trying to do so lately.

*I love sweet things, but then I try to, to not to eat that very much, sometimes I try harder, sometimes I just let myself eat whatever I want, but it`s almost like I try to eat quite healthily (sn9975ff).*

Her Nigerian counterpart who claims to have advanced her ability to control her appetite due to the capacity of HIV to change lifestyle said:

*Now I am, I am 100% careful what I take, and the environment, even my children at home, I protect them because I wouldn't want the situation where I will be down or my husband; is better for one, for me that have already gotten it to be down than others. It (HIV) helps you to change your lifestyle (aw0071fn).*

**Less stress:** Although the stress which is most harmful to health is the emotional one, however, as needful to the body physical stress may be, it is not healthful to cross one`s boundaries (Yle October 2012b). As such, it is essential to emotionally and physically stress less. So a Finnish participant and her Nigerian counterpart say they now stress less. The Finn said she does not push too much even in her academic tasks; she now takes some breaks whenever she feels it is necessary.

*I think if I need I gonna take some time out. I don`t stress so much, I don`t push so much usually, like if I have really difficult in school like earlier too much to do, I just take time out if I need to, am not so hard on myself you know (sh0485ff).*

Then referring solely to less physical stress, the Nigerian said she stops whatever she is doing anytime her body gives her the signal to do so, and the break often remains until she had taken enough rest.

*I try to reduce my working so that I will have enough rest. Very very careful with whatever I do. Even when working, at times when you are working your body system will tell you, you are tied. Immediately I feel so I will stop whatever am doing, am very careful. At least that one will give me time to rest, to have enough rest (aw0071fn).*

**Good hygiene/ An end to sharing shape objects:** Of course good hygiene is essential to avoid infectious diseases, or infecting others. So to avoid making their condition cumbersome, it is necessary for PLWHA to be hygienic. As such, naming some of her recent hygienic lifestyles, a Finnish participant claims that she try to really takes good care of her teeth.

*I try to take really good care of my teeth... (sn9975ff).*

But her Nigerian counterpart claimed to has ceased sharing shape objects as one of her new lifestyles. She now has her own set of hair dressing tools, and no longer shares eyes lips, tooth brush, and similar objects because she is now more conscious of her health. For she does not want to infect others, or have others infect her.

*What has changed in my life, in the past I just, if you have razor blade you have used before, I just borrow it from you. Like I will go to any of my sisters, the eyes lips they have used before I will borrow. Tooth brush I can use any of my sisters` okay you are my sister, you don't have anything, I will use it. You know many thing, even the way of doing my hair, I have my own this thing, before I can go with anything, but now am very conscious of it, I don't want to infect somebody else, I don't want them to infect me (aw0071fn).*

**The biggest reason not to do drugs again:** NordPol (2007) reveals that alcohol and drugs sickens the mind and increase the chances of unprotected sex, which is why getting off drugs` hook and remaining 'drug free' calls for celebration. So a Finnish participant whose testing positive to HIV contributed to her been let off the hook said living with HIV is also the single most important reason why she will not do drugs again.

*The biggest main thing is that is one more reason for me not to try using drugs again (sn9975ff).*

**Strict temperance:** Alcohol consumption among other social norms often hinders efforts to tame the spread of HIV (NordPol 2007). As such it is essential to as much as possible avoid it, and its accompanying habits like smoking and drugging. Two of the Finnish participants claim to have refrained. While one claims she is now alcohol and drug free.

*I live a very very normal life, and except that I don`t drink you know most Finnish people drink, I don`t drink at all, never, I don`t think I will ever again in my, the rest of my life.... Drug free, alcohol free (sn9975ff).*

The other claims she have quitted smoking.

*I quit smoking some years ago (sh0485ff).*

**Balanced diet:** Eating balanced diet is one of the most important aspects of HIV/AIDS counselling, because it sustains strength and body weight, replacing lost vitamins and minerals, and improves the ability of the immune system to fight diseases (FAO 2002, Yle October 2012a). Two of the Finnish participants say they now attempt eating balanced diet. While one claims she is guided by a Finnish food pyramid.

*I eat quite healthily, I try to stay healthy... I try to eat like well balanced, I try to eat fruits, vegetables, meat, potatoes, like you know we have this pyramid (i.e. food pyramid) in Finland (sn9975ff).*

The other said living with HIV motivates one to eat healthy which in return contributes to living normal life with HIV like the diabetics and other chronically sick people.

*Well the fact is that if you eat healthy you live healthy, you live like is with like diabetes and like with all normal people also you live long if you live healthy, obviously, the HIV is also important to eat healthy (sh0485ff).*

**Remaining a vegetarian:** As important as vegan or vegetarian lifestyle may be, many still find it difficult to follow chiefly because it appear to some as the denial of the opportunity to enjoy tasty food. But for a Finnish participant who is somewhat hippie, and has been a vegetarian for about 15 years, sees living with HIV as a good reason to remain so.

*I have been vegetarian for about 15 years, so I eat quite healthy anyway (sh0485ff).*

**Outdoor exercise:** The importance of physical exercise cannot be overemphasised (BBC August 2007, BBC July 2010, BBC August 2011, BBC July 2012, Yle November 2012a, Yle January 2013a). When we talk about exercise what come to the mind of many is 'rigorous or task filled activity'; while as regular walking is simply all the exercise many need, which it is believed to be the best form of exercise. Two of the Finnish participants realising the importance of exercise in mitigating the impacts of HIV say they physically exercise their bodies on regular basis. While one claims she uses walking her dog to exercise.

*I exercise, I go out, move my dog, I like walking (sn9975ff).*

The other claims she regularly squeezes out time from her tight schedule to exercise.

*I try to exercise but well try, meanwhile my schedule at the moment is so busy (sh0485ff).*

**Avoidance of opportunistic infections:** Many experts argue that HIV/AIDS itself does not kill; rather it weakens the body immunity and thereby enables opportunistic infections to run riot and kill the individual. Two of the Nigerian participants practice and encourage others to live in a way that they will avoid opportunistic infections. While one advocates that opportunistic infections should be avoided by all means.

*...those living positively with HIV, taking myself for an example, I try as much as possible to avoid any opportunistic infection. (tp0389fn).*

The other claims that since she tested positive, she stopped going to the saloon, but if she tomorrow chooses to go, she will use her own tools.

*Ever since I got it I don't go to saloon, but if truly I want to go to saloon, I will have my own (as0481fn).*

**Staying in a mosquito free environment:** Although the illness that results from mosquito bites in Nigeria is commonly referred to as 'common malaria', it remains the most common cause of illness and death among Nigerians. Realising how frail her body now is and how prone she has always been to malaria due to her 'AA Genotype', a Nigerian participant said though it has not been an easy task, she pays extra attention to avoiding mosquito bite. One of the ways she does it is by constantly sleeping under a mosquito treated net.

*I will say though am not a very strict person, but I will tell you I can`t stay anywhere where I feel there are mosquitoes. In fact I don't want to get infected by malaria; you know I pay more attention to my surrounding, you know keep the place mosquito free if it is possible. But you know even living in Nigeria, that cannot be 100% attend, but I try as much as possible. I always sleep under mosquito treated net because I don't want to be infected be malaria (tp0389fn).*

She is of course doing the right thing because PLWHA are at increased risk of clinical malaria, severe illness, hospitalization, and death (NMFS2011).

### 4.7.4 Summary of HIV related reformed lifestyles

In this sub-category a total of 17 themes (10 and 7 from the Finnish and the Nigerian participants respectively) emerged on the participants` reformed lifestyles as a result of their HIV-positive status. They reveal that testing positive to HIV had changed a lot in the lifestyles of the Finnish and Nigerian participants. As such, they have dropped most of their unhealthy habits, and now pursue positive and healthy ones. For instance, a Finnish participant said testing positive to HIV is to her a wake-up call which has drawn her attention to healthful living because it made her realise that her body is frail. Another said it made her to improve efforts in taking care of her health even to the point that she neither smokes cigarette, drinks alcohol, or even party. Instead she is now into different kinds of sports, eats healthy diets, resting well, and keeping her spirit high, then for relaxation, also goes to the theatre. Two of the Nigerian participants claim they have also started to live healthfully through eating a lot of fruits, drinking a lot of water, exercising, and relaxing.

Furthermore, three of the Nigerian participants also claim living with the disease has helped them to change old habits. While one claims she now eats large quantities fruits and vegetable every day, another said she no longer takes soft drinks, and now eats beans long before bedtime to avoid troubles with indigestion, and the third said she is now following the healthy lifestyle of taking enough water, eat balanced diet, take fruits, and so forth. For a Finnish participant who is now drug free, living with HIV is the single most important reason why she will not do drugs again. Again two Finnish participants claim living with HIV has made them to begin to attempt eating balanced diet. The disease has also made another Finnish participant who has been binging on sweets to begin to control her appetite, while her Nigerian counterpart said she is now 100% careful with what she ingests. For the other two Finnish participants, living with the disease call for reversing from loosed ways of life into strict temperance which includes: alcohol free, smoking free, drug free lifestyles.

For a Finnish participant who has been a vegetarian for about 15 years, living with HIV is an additional motivation for maintaining the lifestyle. Two other Finnish participants said haven understood the need for physical exercise to their health; they now exercise on regular basis despite their busy schedule. A Finnish participant and her Nigerian counterpart said their positive status had made them to now stress less; emotionally, academically, and physically. Then while a Finnish participant said she now maintains good hygiene by taking good care of her teeth, her Nigerian counterpart said she no longer share sharp objects with other, nor shares eyes lips, tooth brush, and other objects. Two other Nigerians said they now take every necessary step to avoid opportunistic infections which are among the biggest health threat to PLWHA. Finally another Nigerian participant said she does all that she can to make such that she avoids mosquito bite because her body is now frail, and also because she is prone to malaria due to her ‘AA Genotype’. So it seems the lifestyles of the Finnish and Nigerian participants are equally being reformed.

For further insight, concept maps in figures 29 and 30 below separately mapped out the transformations that have taken place in the Finnish and Nigerian partic-

ipants due to their HIV-positive status, and table 32 in appendix VII shows the comparison between the Finnish and Nigerian participants` reformations in lifestyles due to their HIV-positive status, and the comparison was backed with findings from earlier studies. This is the end of the category on transformations after testing HIV-positive (consisting of 2 sub-categories, 31 themes – 15 and 16 from the Finnish and the Nigerian participants` conceptions respectively).

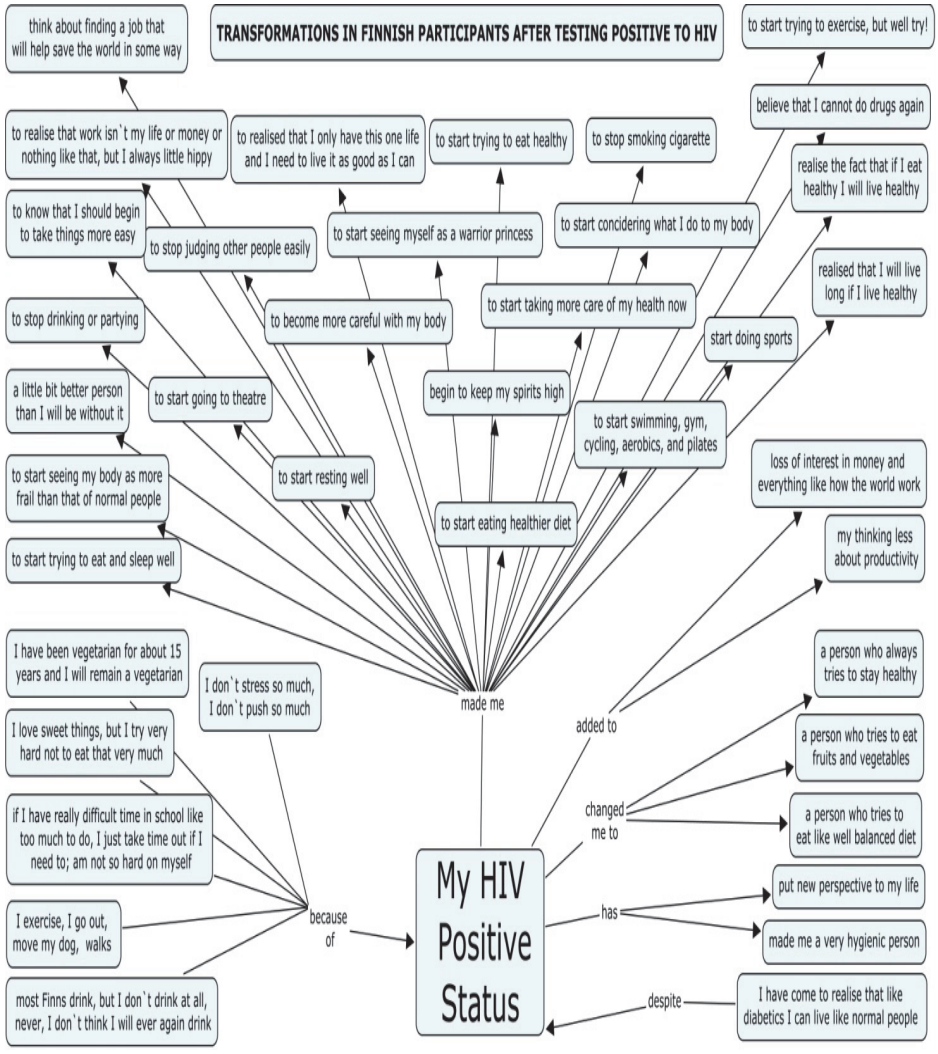


**Figure 29.** Concept Map on the transformations in the Finnish participants

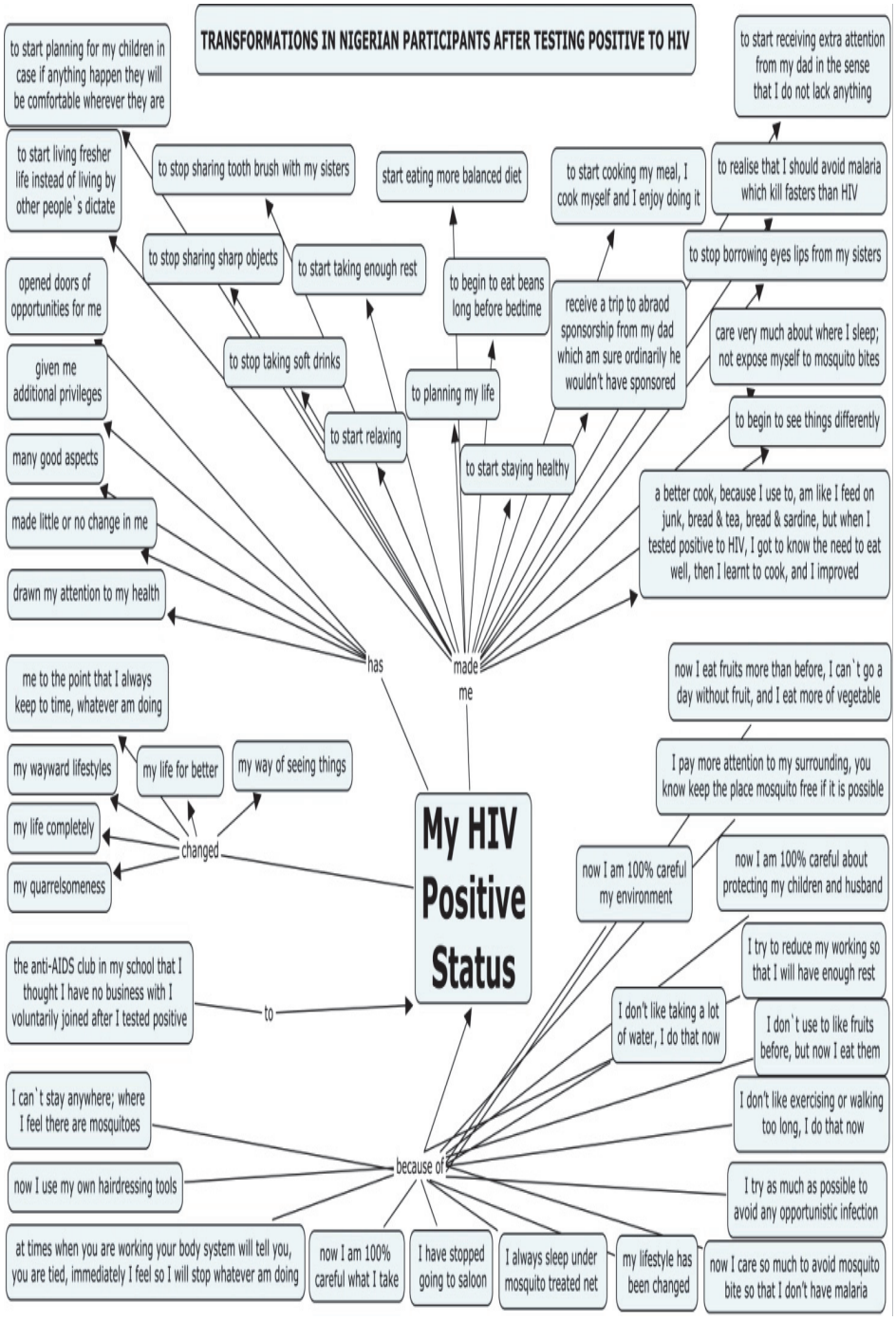


**Figure 30.** Concept Map on the transformations in the Nigerian participants

# 5 DISCUSSIONS AND CONCLUSION

The purpose of this study (see chapter one) is to broadly identify and compare the different meanings HIV-positive Finnish and Nigerian university students give to the disease based on their conceptions (thoughts and experiences) of the disease`s impacts on health (emotional/ mental, physical, and social), education, productivity, and future goals. The aim stretches beyond identifying the negative conceptions of HIV/AIDS to finding out the benefits of living with the disease. This includes pinpointing the positive and healthy lifestyles changes living with the disease motivate. The goal is to use such set of findings to better HIV/AIDS understandings which may contribute to improving the conditions of PLWHA and minimising of the fears of 'students in Limbo'. I also hope that my findings will improve readers` zeal to live healthfully. It seems my findings met the research goals; chapter four reveals that besides the well-known negative impacts of HIV (for which it is always painted 'black'), living with HIV (not AIDS) is also beneficial; in the sense that it gives certain number of privileges, and also enables positive transformation of lifestyles chiefly because it motivates PLWH to attempt improving their health and quality of life. Since this chapter builds on the previous ones, it seems useful to first outline what the preceding chapters contributed to reporting this study.

In chapter one, the research problem and research questions responsible for establishing and guiding the context for this study were introduced. In chapter two, literatures were reviewed to give theoretical framework for the empirical data analysis. Chapter three gave insight on the methods and approaches used in collecting and analysing the empirical data with step-by-step description of the entire process followed. The main tool employed is phenomenography because the study is not aimed at the phenomenon itself (HIV/AIDS) but on the conceptions of HIV-positive students on it. In Chapter four, the comprehensive outcomes of the analysis were described, compared, and mapped in ways readers can easily understand; so it provided a detail account of what this study discovered, and thus formed the bases for this chapter which discusses the main findings of the study.

As shown in chapter four, the study outcomes are quite broad (7 main categories of description, 26 sub-categories, and 300 themes in about 200 pages), as such only the key findings (the most outstanding findings) are discussed here. Although the outcome of this study came in 7 categories (knowledge and understandings on HIV/AIDS, impacts of HIV on emotional/ mental health, impacts of HIV on physical health, impacts of HIV on social health, education-wise impacts of HIV, impacts of HIV on productivity and future goals, and transformations after testing HIV-positive), based on their implications the key findings are discussed here under three new categories namely: 'Negative Effects of Living with HIV, Positive Impacts of Living with HIV, and Positive Lifestyle Changes Due to HIV-positive Status'. Within these new categories, the key findings are also discussed based on the five cardinal goals of this study (as shown in chapter one) which are to find the 'education-wise impacts of HIV, impacts of HIV on mental/ emotional health, impacts of HIV on physical health, impacts of HIV on social health, and impacts of HIV on productivity and future

goals' all of which determine meanings HIV-positive students give to the disease. Doing the discussions this way, will also measure the degree to which my research questions are answered. Then though there are tresses of Finnish Nigerian dichotomy in the outcomes, emphases are not laid on comparing the two in this chapter because that has already been done exhaustively in chapter four, and in the appendixes. Furthermore, in this chapter the conceptions of the participants are generalised without necessarily pointing out who said what because in phenomenographic studies it is the entire conceptions that make the meanings the study is searching for. In addition, tables are used at the end of each of these three categories to further give insight on the findings.

## 5.1 Negative effects of living with HIV

Under this category are discussed the key findings on the negative effects of living with HIV, and these finding are primarily derived from categories one to six of chapter four. Ideally, I suppose to discuss the positive impacts before the negative ones, but I chose to discuss this set of findings first because they are much more in concord with what we already know and thus enables me to go from the known to the unknown. Furthermore, I did not dig too deep into discussing some of the findings in this category become many of them are already well established.

### 5.1.1 Education-wise negative effects

Being a disease that affects the demand and supply of education (Kelly 2001), here are discussed the participants` challenges or embarrassments at school, and the delay the disease inflicted on their academic pursuits.

**Challenges/ embarrassments at school:** Going by the increasing disappearing of middle income earners in the generation, cheap is the friend of many and hardly will an individual go for a more expensive goods or services when the cheaper one is of the same quality. So for a participant of this study to forgo school cheaper health service for a more expensive one just because she would not want anyone within her school to know about her HIV-positive status may mean that she smells some dangers if members of her school community will come to know that she is HIV-positive. Then though no HIV-positive student would want to be embarrassed at school, twice another participant of this study received such embarrassments; the first was by a fellow student who refused to touch her during a physical education exercise, and later by a teacher who asked whether she is still capable of learning. While these experiences may be rare, they revive the need that school environments should be made more HIV/AIDS friendly as argued by Chilisa, Bennell and Hyde (2001). It is mostly in attempt to avoid such challenges that HIV-positive students rarely disclose their status at school, and the fear of such troubles also to a large extent prevents students in limbo from going for HIV screening. So since school age individuals are the most vulnerable to HIV/AIDS (UNICEF, UNAIDS and WHO 2002, UN Women 2011a), it is essential that school authorities begin to plan for protecting

HIV-positive students from these kinds of challenges and embarrassments, but meanwhile Chilisa, Bennell and Hyde (2001) recommend that infected students should use positive living within and outside school premises as a coping strategy.

**Delay of academic pursuits:** Though HIV/AIDS causes double-jeopardy situation which on one hand reduces quality of education and on the other leaves fewer people able to receive the benefits of learning (WHO 2002), the disease seems not to have completely destroyed the opportunity of any of the participants to study; however, in one way or another it interrupted the academic pursuits of more than half of them. For one the interruption was for as much as 9 years chiefly due to HIV-related frequent illnesses. The disease is also responsible for why the participant reads just two days to exams in order not to forget, but even at that she still falls ill after each exam season. Another participant believes that she is now slow, and has trouble remembering things or picturing large entities. Nevertheless, as bad as the experiences may be, it seems they are not worse than the increased absenteeism and withdrawal from school as reported by Chilisa, Bennell and Hyde (2001), or the forfeiting of scholarship opportunity by the Nigerian lady (in chapter one) who`s story greatly contributed to the zeal for doing this study. In addition, one fact that must not be overlooked is that the two participants with these experiences are in their 40s and have lived with the disease much longer than other participants (13 and 20 years respectively). So that the younger participants did not narrate similar experiences could also be because the negative effects of the disease on academic pursuits are already on the decline due to better health care services.

### 5.1.2 Negative effects on emotional/ mental health

This study also confirms that living HIV/AIDS affect individuals mentally and emotionally, which include identity crisis because HIV/AIDS predominant plots do not give true image of PLWHA (Anderson and Spencer 2002, Clarke 2004), guilt (Clarke 2004) because they did not do enough to protect themselves notwithstanding that they knew better, prison of shame because the disease has a stamp of self-infliction (Ibid), depression and sadness (Stevens and Doerr 1993) due loneliness even in the midst of people (Moore 2001, NordPol 2007) which leads to living in bondage and self-stigmatisation (Anderson and Spencer 2002, Cao et al. 2006, NordPol 2007), self-pity because the disease is a constant reminder of inevitable death (Anderson, Ryan, Brown, Gray 1999), and so forth, all of which may lead to suicide thought and attempt (Stevens and Doerr 1993, Anderson and Spencer 2002, Clarke 2004, Préau et al. 2008) because living with the disease may mean additional sorrow in a world full of troubles. But beside all these experiences, one of the greatest mental tortures expressed by one of the participants is the repeated disclosure of positive status at hospitals at every visit despite the fact that most of the visits are not HIV-related. Though from what we already know these emotional/ mental health effects seem to be declining, nevertheless the decline seems to be happening at a low pace. As

such, concerned individuals, organisations, and authorities should continue to initiate means for relieving the anguish of PLWHA.

### 5.1.3 Negative effects on physical health

As well, this study affirms the outcomes of earlier studies which show that living with HIV/AIDS affect individuals` physical health; however, it shows that the effects are not as much as they are often assumed. The most outstanding physical health effects revealed by this study are frequent illness (Lather and Smithies 1997, NMFS 2011), prolonged acute illness (Ogunjuyigbe, Adeyemi and Obiyan 2009), reduction of productive ability (NordPol 2007), and side-effects of medications (NordPol 2007). Singling out the medication side-effects; while studies show that HIV-related illnesses are being decreased by HIV medications (Clarke 2004), and are equally improving the quality of life and the ability of PLWHA to be productive (Echeverria, Jonnalagadda, Hopkins and Rosenbloom 1999), the medications pose their set of challenges. Although it was not until the introduction of the medications that the flame of living gracefully with the disease was kindled (Clarke 2004, WHO 2010b), however, beside their main-effects, numerous side-effects have also been reported (Douaihy and Singh 2001, Clarke 2004, Zimmet 2005, NordPol 2007).

Particularly from two of the participants of this study, obvious side-effects are reported. The one who is a Finn and had lived with the disease for about 20 years reported that HIV medications have caused all the fat on her faces and limbs to move to the waist area making it look like she is pregnant when she is not. She also reported suffering stomach upset, nightmares, rashes, tiredness and several allergic reactions which have led to her being often rushed to the hospital. In addition she argues that even at 45 she has started seeing signs of menopause because the medications have eaten away her testosterone. She further argued that mentally, the medications caused her some level of learning disabilities and troubles. Similarly, her Nigerian counterpart who had lived with the disease for about 13 years reported that the first medications she used made her chick, knee, and buttock to go inside, and her stomach as well swelled as though she was pregnant. Mentally she also reported that they made her forget easily. Nevertheless, when she complained, the medications were changed; noticeably, the new ones have been reducing her blood level which she has been rebuilding with multivitamin supplements and eating of lot of vegetables. Some of the above side-effects are in agreement with findings of studies which show that HIV medications are often responsible for illness, fatigue, depression, chronic disability, profound weight loss and reduced quality of life (Douaihy and Singh 2001, Clarke 2004).

Since the other participants did not also complain about any noticeable side-effects, it seems beside individual differences, the side-effects are felt most by the eldest Finnish and Nigerian participants who have also lived with the disease longer than others. This may probably be because the medications used now have far less side-effects than the earlier ones; which may equally mean that the manufacturers of the medications have already received the message. While this outcome adds to what we already know, the participants believe that

HIV medications will continue to get better, and even the cure will be found during their life time. But meanwhile, in line with Zimmet (2005) counsel, caution should be taken before prescribing medications to PLWHA because many of the avoidable harms caused by wrong prescriptions may be irreversible. Furthermore, as one of the participants observed, the number of pills per day if possible should be reduced because swallowing as much as 12 pills could be a nightmare.

### 5.1.4 Negative effects on social health

This study as well confirms that the social health problems caused by HIV/AIDS are huge, and most of them are centred on stigmatisation and discrimination; the ultimate challenge for PLWHA (Parker and Aggleton 2002, NordPol 2007, Akinbami et al. 2010), forgoing some opportunities, harder task finding life partners, restricted travelling, and nightmares with disclosing positive status.

**Stigmatisation and discrimination:** In agreement with earlier studies, here are some of the discrimination related experiences of the participants of this study. They have received discriminations from home (Honarvar 2010), at church, at school (Chilisa, Bennell and Hyde 2001), at workplace (Clarke 2004), and even at health centres (McCarthy, Koval and MacDonald 1999, Hodgson 2006, Ogunjuyigbe, Adeyemi and Obiyan 2009). These discriminations in one way or another also led to their being self-stigmatised (Cao et al. 2006, NordPol 2007), isolated (Skevington, Norweg, and Standage 2010), negatively labelled which attracted embarrassing questions (Cao et al. 2006), rejection which caused public disgrace and painful separation (Stevens and Doerr 1993).

A former director of the WHO Global Programme on AIDS (Jonathan Mann) in 1987 identified HIV/AIDS epidemic with three phases namely: the epidemic of HIV, the epidemic of AIDS, and the epidemic of stigma, discrimination, and denial (Parker and Aggleton 2002). But what is most disheartening is that the discrimination has found its way into health care centres which suppose to serve as a safe haven for PLWHA; it is even to the point that a doctor refused to deliver the baby of one of the Nigerian participants which led to her making a trip of about eight hours just a day before her delivery. All the Finnish participants as well complained of haven received one discrimination or another from health practitioners. In painting a picture of this reality, Ogunjuyigbe, Adeyemi and Obiyan (2009) reveal that one in ten doctors and nurses in Nigeria admit haven refused to care for HIV/AIDS patients. Of course, for the fear of getting infected, studies have acknowledged the anxiety felt by healthcare workers who come in contact with PLWHA (Hodgson 2006). However, while the health professionals' safety must not be compromised, it is necessary to continually re-educate and update their knowledge on HIV/AIDS so that the unnecessary negative attitude of some of them will begin to fade away because discriminations at the suppose remnant safe haven may be contributing to suicide thoughts or the act itself especially in already suicide prone country like Finland (Yle July 2012).

Sometimes the negative labelling of PLWHA may be hard to bear especially for individuals like the Nigerian participant who remained a virgin until she got married. However, in as much as it is good to guide against external discrimination, going by the counsel of one of the Nigerian participants, PLWHA should not stigmatised themselves either. So instead of locking themselves up at home, PLWHA should regularly attend social gathering fabulously dressed. It is also worth acknowledging that, HIV/AIDS discrimination and stigmatisation seems to have been on the downward sparrow which is for the good all. But while it is necessary to continuously fight HIV/AIDS related discrimination because it leads to low self-esteem and lose of interest for fighting back against the disease (Valdiserri 2002), where necessary HIV/AIDS legislation should be reviewed or amended as the Finnish participants pointed out, especially the laws which consistently portray PLWHA as criminals and others as victims (when safety in sexual matters should be the responsibility of the two involved). The Nigerians participants would chiefly want the attitudes of the police towards them improved [especially when they are reporting cases].

**Opportunities forgone:** Living with the disease also caused the participants to forgo some number of opportunities which include: not attending a first choice university, not thinking about a career in public service (Gachuhi 1999), constantly using condoms with their spouses (WHO 2010b, Durojaiye 2011), loss of opportunity for additional children, not getting pregnant the normal way, and not breastfeeding their babies (Anderson and Spencer 2002). The forfeits are for two main reasons – health and avoidance of discrimination. These two have been at the centre of every challenge PLWHA face everywhere in the world. So it is essential that all those who are related to PLWHA should try as much as possible not to worsen their already pitiful conditions. For instance the Nigerian participant whose first husband sent away said she believes that it was orchestrated by her former mother-in-law because she did not breastfeed her baby. Similarly, she believes that not breastfeeding the child she is expecting in her second marriage for the same health reason may pose related challenge. So while the opportunity of PLWH to breastfeeding their babies may not be completely lost as medications continue to advance, their mother-in-laws in Nigeria should learn to be considerate especially in matters beyond their daughter-in-laws` control. Then as much as it is possible, PLWHA should minimise their self-inflicted opportunity costs, and the efforts should be supported by authorities through making their communities more HIV/AIDS friendly.

**Harder task finding partners:** Particularly the Finnish participants believe that the disease has made finding life partners much harder (NordPol 2007) partially because the PLWHA in Finland are few (UNAIDS/WHO 2008). In Finland unlike in Nigeria it seems culturally accepted for a woman to make the first move in kick-starting a relationship. But because two of the Finnish participants who are not presently in a relationship would prefer to keep safe distance from men, they lack the courage to make the necessary move, as such they believe that relationship-wise the disease is really hurting them. It is unfortunate that these participants are compelled by their societal thoughts of the disease to think

and act the way they do. They further argue that, it is especially due to the unethical way the Finnish media portray them as contagious evil people who want everyone else to get infected with the disease, and that somehow make them prefer to keep safe distance from men. So while it may seem that singleness in Finland is on the increase (Yle January 2012, BBC March 2012), the situation should not be made worse for the HIV-positive Finns due to their being wrongfully portrayed. Then on their own part, they too can borrow live from their Nigerian counterparts who see living with HIV/AIDS as an opportunity even to marry within the community of PLWHA.

**Restricted travelling:** It may sound strange that in the 21st century one of the challenges PLWHA still face is restricted travelling (Clarke 2004). It is understandable that in the later 20th century some countries including US, China, Finland, and so forth had placed travel ban on PLWHA some of which lasted till the early part of this century, but that up till now there are still travel restrictions on a disadvantaged group which poses no national security threat to any nation-state sounds ridiculous. So the countries still upholding such policy should soon reconsider their stand.

**Disclosure a nightmare:** HIV-positive status disclosure in some sense is beneficial (Pennebaker and Beall 1986, Pennebaker, Colder and Sharp 1990, Greenberg and Stone 1992, Derlaga, Metts, Petronio and Margulis 1993, Kalichman, DiMarco, Austin, Luke and DiFonzo 2003, Clarke 2004), but the act sometimes becomes a nightmare because of its being linked to dying (Anderson and Spencer 2002) especially by family members, which is why it is easier to disclose to friends (NordPol 2007). In the light of this, Honarvar (2010) therefore admonished counselling of the family members of PLWHA because it may influence remarkable decrease in their negative behaviours.

### 5.1.5 Negative effects on productivity and future goals

Two outcomes (distorted future, and fears and worries) are discussed here, and they also confirm the findings of earlier studies which show that living with HIV/AIDS crack dents on an individual`s ability to plan for his/her future, especially future career (Gachuhi 1999, Clarke 2004), and that the disease increases an individual`s fears and worries.

**Distorted future:** The participants of this study believe that their lives have been somehow distorted by the disease, and this includes their plans for the future. One of the Nigerian participants specifically stated that her future will likely be challenged by hardship due to her inability to work as hard as she use to. But because help for fixing such will not fall from heaven, the participant managed to return to school after nine years after dropping out so that she will be able to find less physically demanding job that may grantee her retirement benefits. So others who suspect that their future has been greatly distorted by the disease could as well begin to do something on their own to better their future while they wait for external supports.

**Fears and worries:** About eight harboured fears and worries were expressed by the participants. Four of them have to do with people knowing about their positive status, three about the medications effects (including the fear that there is no cure in sight), and the last one is on problem with solitude. All the fears and worries are consistent with what we already know. On the fears of their positive status being exposed, Issiaka et al. (2001) argue that even some of the PLWHA have problem trusting one another. Then concerning the medications, undoubtedly their side-effects have been decreasing, but solitude remains a major social health problem for PLWHA. For instance according to NordPol (2007), 59% of respondents believe they are alone despite the fact that they prefer people`s company. So though some of these fears and worries have continued to die natural death, the manmade ones should be tackled too so that life could become more pleasant for PLWHA. But looking at the future of PLWHA from where we were and where we are now, it seems things will continue to get better. All of these findings affirm that in deed as earlier studies suggest, the emotional/mental and social health challenges of living with HIV may be worse than the physical health and other ones, so tackling them is essential. In addition, table four below shows the sub-categories and themes under which the key findings on the negative effects of HIV in this study are discussed.

**Table 4.** The negative effects of living with HIV.

| Num. | Education-wise effects | Effects on emotional/ mental health | Effects on physical health | Effects on social health | Effects on productivity and future goal |
|---|---|---|---|---|---|
| **1** | Embarrassments at school | Identity crisis | Frequent and prolonged illness | Stigmatisation & discrimination (negative labelling, embarrassing questions, rejection, isolation, public disgrace & painful separation) | Distorted future (hardship due to less productivity) |
| **2** | Delay of Academic Pursuits | Guilt | Becoming less productive | Opportunities forgone (choice university, cheaper healthcare, career in public service, usual intercourse, additional children, pregnant the normal way, and breastfeeding) | Fears and worries |
| **3** | | Prison of shame (a stamp of self-infliction) | Medications side-effects | Harder task finding partners (standing out) | |
| **4** | | Depression & sadness (loneliness & living in bondage) | | Restricted travelling | |
| **5** | | Self-pity (constant reminder of death) | | Disclosure a nightmare | |
| **6** | | Suicide thought & attempt (additional sorrow) | | | |
| **7** | | Repeated disclosure at hospital | | | |

## 5.2 Positive impacts of living with HIV

Under this category are discussed key outcomes which reflect the positive sides and benefits of living with HIV (not AIDS). The key findings were also primarily derived from categories one to six in chapter four. They agree with few recent studies which argue that despite the fact that living with HIV has numerous negative effects, the condition also handsomely benefits individuals educa-

tion-wise, health-wise (emotional/ mental, physical, and social), productivity, and future goals-wise. As part of the new set of findings on HIV/AIDS studies, it is also worth noting that the findings discussed in this category are not in congruence with what we already know about the disease especially in the 1980s and 1990s nor very popular in the HIV/AIDS literature.

### 5.2.1 Education-wise positive impacts

Though it may sound unpopular, the fact is that education-wise impacts of living with HIV are also beneficial. Here are discussed two education-wise positive impacts of living with HIV (bettering of HIV/AIDS awareness and understandings, and improved zeal for academic pursuits).

**Bettering of HIV/AIDS Awareness and Understandings:** Exposure-wise living with HIV seems beneficial; for it gives better opportunity to deeply explore knowledge on the diseases, and the acquired knowledge being power (WHO 2002) enables one to begin to see the disease differently. Generally many prefer to hold on to their HIV/AIDS` ignorance or 'the outdated scratch on the surface' which rumours around, and then continue to tremble at each time the disease is mentioned. It is likely that the exceptional fears of the disease are due to limited or lack of HIV/AIDS knowledge, and the predominant lack of desire to explore facts about the disease has continued to do havocs. For instance, due to lack of clear HIV/AIDS understandings, many still see the disease as a contagious scary and deadly disease that must be avoided at all cost, which is why more than 50% of Nigerians go to the extreme of refusing to shake hand, hug or share the same toilet with PLWHA (Ogunjuyigbe, Adeyemi and Obiyan 2009). Such attitude has been kept alive for about three decades just because people do not really know or care to know that the disease cannot be contracted through such means. Nevertheless, test HIV-positive makes the difference because according to the participants the desire to explore facts about the disease naturally develops once an individual tests positive.

Prior to their being diagnosed with HIV, the participants of this study like many others had no broad knowledge on HIV/AIDS, but that changed shortly after each of them were confirmed HIV-positive. After the confirmation, impressions in the Finnish participants that HIV/AIDS is something that happen in Africa disappeared and gave way for logic, and the common phrase 'is not my portion' ceased from the lips of the Nigerian participants. Each of them at once became driven to dig deeper and deeper in search for the prone and cons on the disease of which they have always ignored despite their being frightened by it. So the fact of the matter is that, it is being diagnosed HIV-positive that triggers most the desire to explore HIV/AIDS knowledge which breaks the yoke of its ignorance. The explorations come through books, internet, conferences, workshops, support group meetings, and so forth. Even a Nigerian participant who earlier thought she has nothing to do with the anti-AIDS club in her school voluntarily joined the group afterward. The study also shows traces of desire to

know being triggered in some of the family members and friends of the participants after their positive diagnosis.

Furthermore, HIV/AIDS is greatly feared because deep inside some is the feeling that if they go for the screening, they may be diagnosed HIV-positive due to their past carefree lifestyles, but in their paranoia are too afraid to go for the screening which is the most reliable way of knowing one`s true status. For it is by going for the screening that the individuals in limbo will know their true fate. By so doing, those whose test results are negative will find peace of mind, then those whose results are positive; though no one wants such result, but with the present developments it is not that bad because knowing one`s positive status gives the opportunity to seek for deeper HIV/AIDS knowledge which has made many to come to peace with their positive status, and many of such individuals are also taking necessary steps to prolong their lives, and avoiding infecting others too (Porter, Wall and Evans 1993, WHO 2010b).

Therefore, it seems the importance of getting screened is huge which is in consistent with what we already know. For it does not only put the minds of those who test negative at rest, but also arouse the desire to know in those who test positive which leads to the exploration of facts about the disease and doing away with the myths and fables long held on to, as such total change in HIV/AIDS conceptions is enabled. It is probably the prior lack of the desire to know in the Nigerian lady (in chapter one) that made her choose forfeiting a scholarship placement in the US after being diagnosed with HIV. So since HIV screening contributes greatly to becoming better informed about HIV/AIDS, the Finnish and Nigerian governments in making their HIV/AIDS policies should consider the essentiality of promoting HIV/AIDS screening for all.

**Acquisition of power:** Because the participants became better informed about HIV/AIDS after testing positive, their views of the disease became also drastically changed from a contagious life devourer to a chronic one (like diabetes) (Baumgartner 2007) or even just a disease like every other. Then the new conception serving as a platform enabled them to also acquire knowledge on healthy living principles which further empowered them to move on with their life. So it seems acquiring healthy living knowledge largely contributed to their strong confidence and resilience to withstand the disease probably because the acquisition was coupled with a given degree of knowledge on human physiology of which many even among the literates have abandoned to health practitioners when ideally is the branch of education which everyone deserve a reasonable piece of; lack of which may have contributed to why many abuse their bodies and thus put their health and life in danger.

Then beside public campaigns through the media and similar avenues, the participants suggested direct involvement of PLWH in taking the crusade to two major institutions – schools and HIV screening medical centres. They suggested schools because students' sexual knowledge influence their sexual health behaviours (Herdt and Howe 2007), and also because it is where to catch them young. The reason why they also suggested HIV screening centres is discussed later in this category (under the theme – 'Finding a Career in Educating People about HIV/AIDS'). So the participants` receiving of the right HIV/AIDS

knowledge after their HIV-positive diagnosis empowered them, and also motivated the zeal of some of them to consider empowering others. Therefore, since HIV/AIDS and healthy living knowledge is power for taming the spread of HIV/AIDS and also for mitigating the disease`s impacts on PLWHA, sharing such knowledge should be well utilised by individuals, organisations, institutions, governments, and other bodies on whose shoulders fall the responsibility to do so for positive transformations to be initiated.

**Increased zeal for academic pursuits:** There are many factors which decrease individuals` motivation and zeal to study, and they vary geographically. But 6 out of the 7 participants (3 apiece) argue that being diagnosed with HIV instead of killing their motivations to pursue their studies actually increased it. One of the Finnish participants even argued that testing positive helped her to recover from lousiness which was actually the discouragement factor to her studies. Of course the academic pursuits of some of them was temporarily interrupted by the disease, but on the long run test positive further motivated them to study because they needed to proof to themselves and others that the disease has not decreased their academic strength. Particularly for the Nigerian participants, the increased zeal is also because seeing their future in the light of the disease; they saw it necessary to improve themselves academically in order to secure their future. This outcome though surprising, one may not attribute it just to Finnish sound education system because if that is the case, the Nigerians whose education on its own is a challenge would have shown different result. The outcome refutes what has always been ascribed as HIV impacts on academic pursuits which include increased absenteeism due to frequent illness and lose of interest to study (Chilisa, Bennell and Hyde 2001). Therefore, this outcome sends signal of relief to students in limbo who are afraid that finding out about their HIV-positive status might hinder their academic pursuits. In the light of this finding, perhaps the Nigerian lady (in chapter one) who forfeited the offer for a scholarship in the early 1990s might have reacted differently today. But because her story was not followed, it is not known whether she changed her mind after becoming better informed. But is is worth acknowledging that unlike individuals with advanced AIDS, the participants of this study are relatively healthy literates living in urban settings who tested positive only to HIV. So perhaps the outcome might have been different if they were illiterates living with AIDS in rural settings.

### 5.2.2 Positive emotional/ mental health impacts

The most outstanding findings singled out for discussion here are the fulfilment in the participants that there are still chances of falling in love, the opportunity of finding HIV-negative partner in an age characterised with decreasing commitments (Yle January 2012), and high chances of giving birth to HIV-negative children.

**There are still chances of falling in love:** As the world gets transformed into a virtual one, solitude is increasingly becoming a health problem not only for

PLWHA. According to NordPol (2007), 59% of PLWHA believe that they are alone despite the fact that they prefer people`s company. As a cushion to such challenge, most of the participants argue that their viral load is very low (even undetectable), and as such they may not easily infect a partner which is in agreement with a recent trial which shows that antiretroviral therapy can reduce the chance of infecting a HIV-negative partner by up to 96% (WHO 2011). So to show that this is not just a theory, 5 out of the 7 participants are presently in relationship with HIV-negative men and there is no record that any the men have been infected.

**HIV-negative husbands and children:** Although the Nigerian participants see their fate as an additional opportunity for finding spouses within the community of PLWHA. Fortunately four of them plus a Finnish participant are in relationship with HIV-negative men. Except for a Nigerian participant who was already married prior to her positive diagnosis, in the case of the other four relationships, the men knowingly accepted going into relationship with the HIV-positive ladies, and on some occasions one of the Nigerian couple do not even use condoms. The questions that may arise in the minds of many could be – why in the world did the men chose to take such risk? Are they really in their right senses? And so forth. In an attempt to contextually debunk such questions based on the outcome in chapter four, I will argue that the men knowingly entered into the relationships because unlike many others they are well informed about what HIV is and what it is not. More also, as the participants claimed, the men are also aware that what their spouses have is HIV and not AIDS. Again as the ladies claimed, the men are aware that their spouses` viral loads have been reduced to undetectable and as a result they may not be infected easily. So the reduced fears is consistent with studies which suggest that even male circumcision (common in Nigerian) alone can reduce the risk of acquiring HIV though sex (WHO 2010b). Furthermore, while a newly FDA approved drug is said to have 44% to 73% capacity to prevent HIV infection (BBC May 2012), another trial shows that antiretroviral therapy can reduce the chances of infecting a HIV-negative partner by up to 96% (WHO 2011), yet another recently concluded trial of Simian Immunodeficiency Virus (SIV) vaccine on monkeys proved very effective (Hansen et al. 2013). Nevertheless, most of these men have stick to constant use of condoms.

Of course this outcome does not give license for promiscuity and unprotected sex because it is not everyone living with HIV that has low viral load, and even the newly approved drug and other trials do not guaranty 100% protection against the disease. Also besides HIV/AIDS, there are numerous STIs that are very infectious and deadly. What the outcome rather established is that to some extents, the PLWH are not as infectious as they are usually seen. So the suggestion by some Finns that they should be sent to unused leper colonies (Clarke 2002) holds no water, and the fear of more than 50% Nigerians not to shake hand, hug or share the same toilet with PLWHA (Ogunjuyigbe, Adeyemi and Obiyan 2009) is uncalled for. In addition, the fear of many that once they are diagnosed with the disease, their chances of finding a partner (especially a HIV-negative spouse) would have be completely ruined is hereby refuted by this

outcome. Furthermore, five of the seven participants have had a total of seven children (two from two Finns and five from three Nigerians) and none of them is HIV-positive. So unlike the earlier days of the disease when mother-to-child infection was high, the incidence has significantly reduced. Even the participants who have no kids yet nurse no fear of giving birth to HIV-positive children because the current trend does not give room for such fear. So, that there are still chances of finding a HIV-negative partner after positive diagnosis, and that the chances of mother-to-child infection have significantly reduced further show that many of the serious challenges PLWHA use to face and fears nursed by those in limbo are fading away.

### 5.2.3 Positive physical health impacts

Paradoxically instead of living with HIV seriously hurting the physical health of the participants, it is actually their physical health and life restorer, which is why some of them argue that they are even healthier than before their diagnosis. Besides, it has given them the opportune for free regular medical check-ups and medications in the age when medical services are becoming increasingly unaffordable (Yle June 2012d). Some of them even see themselves healthier than those who have not being diagnosed with HIV. Then the repeated crying due to the initial shock of being pronounced HIV-positive actually benefited them, because a person who feels secure enough to cry and release inner emotion can be quickest to recover since shedding tears gives a person the opportunity to begin to heal and recover from a loss, disappointment, grief, and so forth (Orr 2003).

**Health and life restorer:** One of the Nigerian participants claims that she used to suffer from malaria frequently due to her AA blood genotype that made her prone to malaria, but after being diagnosed with HIV and she began to follow healthy lifestyles learned after the diagnosis (one of which is regularly sleeping under mosquito treated net bed), her reoccurring malaria is now gone, and she hardly suffers from the disease of which the 91% of the 655,000 estimated death in 2010 occurred in African (NMFS 2011). Another who had TB (one of the most common HIV/AIDS opportunistic disease) also used healthy lifestyle to support her medications, and now instead of the extremely acute illness which led to her being diagnosed with HIV in 2004 when she had little or no hope of surviving, she is now in perfect health. It seems one of what makes being diagnosed with HIV/AIDS unique from other illnesses is that unlike the situation where patients show little or no concern about exploring the diseases they are suffering from or make changes in their lifestyles to prevent reoccurrence, many individuals diagnosed with HIV/AIDS soon after begin to gather as much information as they can about the disease, and in addition learn and apply healthy lifestyle which is why unlike the way many see them in the 1980s and 1990s, PLWH are often very healthy individuals with no physical trace of illness (Clarke 2004).

Yet another Nigerian participant saved the life of her sister who had a strange illness which led to her being locked up in a room to die after all hopes

were lost. This participant was able to save her sister`s life because she tested positive to HIV shortly before the incident, and because she spotted HIV/AIDS symptoms in her sick sister and at first administered her own medications and subsequently purchased more for her which she continued to use until she recovered. But supposing this participant was not diagnosed HIV-positive around that time, and she was not also willing to open up to her family, perhaps her then very sick sister might have died about 13 years ago. So though earlier studies have shown that testing positive to HIV in some sense serves as a life saver, this outcome is unique.

Furthermore, a Finnish participant who believed that her life was being wasted away in some strange way as a result of her drug addiction recovered shortly after testing HIV-positive when her struggle with the addiction came to a crossroad, and as such she sees being diagnosed with HIV as a paradox. Like many others, this participant was so addicted to drugs that besides its being responsible for her getting infected with HIV, it also pushed her into vices, but now she is completely drug free. Since she could not quit after several attempts until her being diagnosed with HIV motivated her to go for the rehabilitation which helped her to, so she now sees living with the disease as a lifeguard and also one of the most important reason why she will not do drugs again.

There are many stories of youngsters in an attempt to experiment drugs got hooked and became useless, ruined, and died at very youthful age. So the best option remains never to experiment drugs, but for those who are already hook, the best thing is to quit probably through a rehab or through the help of an expert. But based on the experience of this participant, I will suggest that those who have been finding quitting very difficult should voluntarily go for HIV screening. Perhaps a HIV-positive result might give them the most wanted motivation and strength that to quit. For if not for the help of a quick screening at a needle exchange centre, this participant might have died of drug addiction about a decade ago without either quitting the drugs or beginning to live healthfully both of which have contributed to her life returning to normal and her health restored. So while the Finnish government policy which introduced the quick HIV screening at needle exchange centres is worth praising and emulated by others, further policies that will encourage other groups` quick screening should be looked into because despite HIV/AIDS fears this outcome also shows that knowing about one`s HIV-positive status which positively transforms an individual pays than it hurts.

**Healthier than before:** Being positive about their fate (which is a medicine of its own) may have contributed to the participants` being healthier than before (Szaflarski et al. 2006), and this is in agreement with Fryback and Reinert (1999) which reported that cancer and HIV/AIDS patients who are positive about their diseases have better quality of life than before they were diagnosed positive. So with positive state of mind the participants of this study turned the table to their own advantage in contrast with many who pity PLWH due to the assumption that they are constantly in pain and may most likely die younger than usual. Some of the participants claim that as a result of getting better informed about the disease, adhering to their medications, and changing few life-

styles, they are actually healthier than some HIV-negative contemporaries who believe that they are after all not chronically sick. Many of the participants also believe that they will most probably die in their old age probably not due to their HIV-positive status. Of course this view is far different from the HIV media`s death sentence projections in the 1980s and 1990s of which the hangovers still linger in the minds of many. This new image projected by the very individuals who know where the shoe pinches seems to make HIV screening appears what it really is – 'an opportunity for good health' instead of 'a pathway towards suicide mission' as held by many.

**Free regular check-ups and medications:** One of the most outstanding privileges PLWHA enjoy is free medical services, mostly in form of medical check-ups and medications, and it may have given them some health advantages over others. The free medical check-ups enable among other benefits early detection of other deadly diseases like cancer and heart disease. Although the two are among the greatest cause of mortality in the world; many of those whose were diagnosed early recovered. So while many ignore symptoms that call for medical examinations and treatments due to reluctance and increasing costs of medical services, PLWHA receive such services free in many countries. The medications on the other hand boost their CD4 count and decrease their viral loads, and as such gave them the opportunity to be productive (WHO 2010b) with less absenteeism from work (Beard, Feeley and Rosen 2009). In fact, the most significant impacts of the treatments are that more PLWHA are alive today and are coping with the disease (Clarke 2004).

Therefore, although nothing seems to be actually free in this expensive generation (except for natural endowments) because whatever is tagged free like HIV/AIDS medical services and medications are free not because they cost nothing but because they have been paid for by a government and/ or other international bodies. So while HIV medications and other medical services cost so much, most of the PLWHA do not pay for them on their own. However, the trend seems to be changing in Nigerian where the participants said beside the HIV medications, they are now being charged for other medical services. So though Nigeria may have other priorities, empathically looking at the plights of the PLWHA in Nigeria and how they may not on their own be able to afford the cost of medical services which they constantly need, the government and the international bodies that have been footing the bills should not watch while the situation of the PLWHA in Nigeria get worse due to their inability to afford the cost of the medical services they need.

### 5.2.4 Positive social health impacts

Six out of the seven participants of this study argue that somehow living HIV is socially beneficial. For instance, in a world of increasing moral decay and promiscuity, they see the fear of getting infected with HIV/AIDS to be instrumental for the return of marriage fidelity. Testing positive to HIV has also helped some of them to put to test the love of their family members and friends. Then living in a society where many marriages end in divorce, a Finnish partic-

ipant sees living HIV as a reason to hold on to the relationship she shares with her HIV-negative boyfriend for life. In addition, both groups said they regularly hold support group meetings where they freely share their challenges and sort for help, but a Finnish participant wishes that her group meets more often. As far as disclosure of positive status is concern, the Nigerian participants are more open than their Finnish counterparts. Living with the disease has also drawn most of the participants closer to God, which has been contributing to their coping with the disease gracefully.

**Return of marriage fidelity:** It is unfortunate that the world is becoming outrageously promiscuous as many things are becoming sexualised. From different angles, individuals are increasingly bombarded with nudity, and against the will of many, dozens of nude images are loaded into the minds of many through television programmes, home videos, internet, posters, billboards, books, and so forth. In addition, on daily bases live offensive images are seen in campuses, streets and neighbourhoods. Some images that were classed taboos few generations ago are now not just tolerated but serving as the 'new normal'. Even the fads of our generation have become so bent that dressing (especially among the ladies) is seen to be abnormal if some of the sensitive part of the body are not left uncovered. Since the mind somehow stores received images, the sights often provoke the sense of lust in many, and that might have been contributing to why in the last few decades married infidelity has gotten worse and moral values vanishing into the thin air or even flushed down the toilet. Illicit sex has become so popular that many no longer see anything wrong with the act which increases the risk of getting infected with HIV/AIDS and other STIs (Durojaiye 2011). So in this age of high marital unfaithfulness, this study shows that the fears of getting infected with HIV/AIDS somehow discourage individuals from becoming too loose, and many are being compelled to constantly use condoms (WHO 2010b). Actually, self-control that is manifested through total abstinence is the sure safety against getting infected with HIV/AIDS and other STIs, and though condoms are the next best option for those who cannot control their sexual urges outside marriage, the fact remains that they do not provide 100% protection. Even one of the Nigerian participants believes that besides not infecting others with her HIV, she will never in her life indulge in illicit sex because HIV virus is tricky, so she does not want others to infect her with their own HIV type which may prevent her medications from working. So even in the midst of numerous sexual provocations as seen in the world today, many are compelled by [if no other reason] the risk of getting infected with HIV/AIDS to remain faithful to their partners, and others constantly use condoms during their one night stand intercourses. Another advantage of this HIV/AIDS risk induced trends is that it is somewhat checking overpopulation. Though some may argue that high level of marriage infidelity still exist despite the HIV/AIDS infection risk, nevertheless, overwhelming evidences show that without such risk things would have been much worse (Durojaiye 2011).

**A test for true love:** It is a pity that many relationships are being ruined today due to selfishness which is engulfing the world. As a result of that, instead of

the ideal 'give and take' that should mare a relationship, 'self-love' is now the order of the day. So because of the present state of things, one of the most effective way [and time] to identify true friends and concerned relatives is the time of need, just as it is often said – 'a friend in need is a friend in deed'. Therefore, due to the scary nature of HIV/AIDS, living with the disease is a perfect opportunity for knowing who is who among friends and relatives. Two of the Nigerian participants were enabled by their condition to beyond reasonable doubt become convinced that their HIV-negative husbands truly love them. While one was convinced by her husband`s efforts in making sure she did not die, the other had the opportunity to compare between her first and second husband and saw that the second truly loves her unlike the first who use to broadcast her HIV-positive status to their neighbour at each time they quarrel, and also divorced her when her baby was just two weeks old. So seeing that their husband truly love them unlike the increasing practice of abandoning marriage vows when the going gets tough, they have also decided to reciprocate the love unconditionally. So, while 'marriage vows' one of which is 'to be there for the other spouse in times of plenty and want is increasingly made void as though the promises made before the knot is tied is nothing but a fulfilment of righteousness, the above Nigerian participants, being diagnosed with HIV see their condition as a reliable tool for measuring their spouse love.

Another Nigerian participant after her diagnosis was well provided for by her dad who will not want to see her depressed, he even went to the extent of sponsoring her recent tourist trip abroad just to make sure that she is not depressed by her condition. Perhaps he is doing this because he cannot stand the chance of losing his beloved daughter at youthful age. Maybe he might not have realised how much he loves her if she had not tested positive to HIV. The fourth Nigerian participant as well was able to know that her elder sister`s love for her is real when after her HIV diagnosis the sister still accommodated her in their small apartment where she lives with her husband and three children despite the fact that she also had TB. In addition, some of her some friends instead of being scared away by her HIV-positive status, they even contributed money to pay for medical treatments during acute illnesses. So with the above facts, it seems being diagnosed with HIV also provides the right forum for identifying those who truly love one.

**Steady relationship:** A casual HIV-negative male friend of one of the Finnish participants amazingly requested for a deeper relationship shortly after she disclosed to him. Although they have been living together for over five years, and some of the differences and challenges that make couples in the western world separate would have started manifesting, this participant plans to spend the rest of her life with him for such gesture. Such decision by a young Finn who is still in her twenties is somewhat surprising especially because in Finland most marriages end in divorce, so being diagnosed with HIV did the magic. As the participant further said another reason why she plans to stay with him for life is that she does not want to expose herself to the difficulty of finding another partner like some of her HIV-positive friends who are still single despite their strong desire for a partner. With this outcome it seems testing HIV-positive

contributes to steady relationships even in Finland and other western societies where couples easily separate over slight disputes which could be resolved easily without considering the impacts of their separation on their children and societies since the family is undisputedly the fabric and pillar upon which a strong society is built. The participant did not indicate whether they have the plan of getting married, but since unlike in Nigeria the Finnish society accepts cohabitation, the most significant thing is that unlike many couple who [despite their marriage vows still] separate; separation is one vocabulary that does not (or no longer) exist in this participant`s dictionary, and it seems many other PLWHA in Finland will behave the same way.

Furthermore, as shown by the census data analysis of 424,000 Finns and 57,000 Brits long marriages lengthens life especially that of men, while singleness decreases it (Yle December 2011). Similarly, a recent study of 15,000 Finns between 35 and 99 shows that single people are 60% more likely to suffer heart attacks than married ones (Yle January 2013b). So though for various reasons no nation-state would want to see her HIV/AIDS proportion increased, but supposing the proportion of PLWHA in Finland was more than what it is now, perhaps the disease`s influence in upholding marriage bonds would have been more noticeable; perhaps reflecting what the marriage proportion was in the Finnish society about a century ago.

**Drawn closer to God:** Five of the seven participants (One Finn and four Nigerians) are religious, and they expressed how testing positive to HIV did not only draw them closer to God but have also made them better individuals. This outcome is consistent with studies like Anderson and Spencer (2002, 1348) where one participant in expressing how living with AIDS has transformed him says: *"If I didn't have AIDS, I'd probably still be out there drinking, drugging, and hurting people. I turned my life around. I gave myself over to the Lord and Jesus Christ".* So since living with HIV/AIDS draw people closer to God and also make them better individuals, it seems in the face of increasing 'vices and crimes', being diagnosed with the disease somehow contributes to bettering our societies. Furthermore, these five participants claim that they are gracefully living with the disease despite all its challenges. They also expressed strong trust and hope in God`s ability to heal them, which is in agreement with Fryback and Reinert (1999) which show that spirituality in HIV/AIDS and cancer patients is influential to the patients` capacity to cope with the diseases. So though many do not buy the idea of being religious, studies show that it is beneficial even to health (Maki 2005), and testing HIV-positive seems to encourage becoming so.

**Support group meetings:** Support group meetings have been very instrumental to meeting the physical, psychological, and financial needs of PLWHA (Harris and Larsen 2007). The Nigerian participants claim that they use it as a forum for sharing their inner most thoughts, needs, and experiences with their fellows with high expectation of meaningful contributions toward overcoming diverse challenges in their daily life. With such forum, individuals` challenges which once seem like unmoveable mountains are resolved through receiving soft

loans, finding spouses, and so forth. Although the Finnish participants also claimed that support group meetings have been very instrumental to helping them cope with the disease, their responses make the meetings sound a bit conservative especially when compared with that of the Nigerians. So seeing the benefits of such meeting, one of the Finnish participants suggests it should be more in Finland, in order to strengthen familiarisation with each other which combats the feelings that one is suffering alone. Although the financial costs of hosting such group meetings may be high, but for its numerous benefits, the individuals and organisations that sponsor such meetings should continue because such support is not just to the individual recipients but also to their societies.

**Disclosure of positive status is beneficial:** Despite the challenges with disclosing positive status (Kimberly, Serovich and Greene 1995), some of the participants of this study have had good experiences with disclosing theirs (Pennebaker, Colder and Sharp 1990). For instance, it was from disclosing to a church member that a Nigerian participant got a link to the medical centre where she received her first treatment. For another, it was through publicly declaring her status at school that she became famous which later gave her the opportunity of being hired by a HIV/AIDS organisation. Another voluntarily uses her disclosure as a tool for making new friends and counselling disheartened newly diagnosed HIV-positive individuals. Yet another said the increasing number of PLWH in Nigeria who are publicly declaring their status has been instrumental to keeping hope alive, and preventing HIV-positive individuals from hiding and dying in silence. Then one of their Finnish counterparts through disclosing to her friends found a life partner, while another said she had noticed that at each time she discloses to a stranger, a strong relationship is established and the individual begins to share with her some of his or her private matters. So, that these six out of seven participants had wonderful and beneficial experiences from their disclosures show that it is likely that HIV-positive disclosure nowadays pays more than it hurts. Besides that, another benefit is that as proven by Pennebaker, Colder and Sharp (1990), PLWHA who disclose their positive status demonstrate normal immune function and are less likely to frequent hospital than those who keep their positive status away from others. So despite the fears of being discriminated or stigmatised, when the situation permits HIV-positive status should be disclosed; if for no other reason, at least for the benefit of demonstrating normal immune function and not frequenting hospital.

### 5.2.5 Positive impacts of HIV on productivity and future goals

This study also shows that, living with HIV instead of being an excuse for not working, it motivates it; and working itself contributes to the minds of HIV-positive individuals being taken away from any virus in their bodies. It also improves their chances of remaining financially independent (Koopman et al. 2000). Furthermore, the change in the participants` HIV/AIDS conceptions after testing positive opened the eyes of some of them to see that there is an oppor-

tunity for building a career on educating people about HIV/AIDS. In addition, they have hope for a bright future.

**Working and remaining financially independent:** Against all odds, the participants of this study are very enthusiastic about working because it among other benefits contributes economically to them and their societies (McReynolds 2001), and also distracts them from thinking about a virus in their bodies. For instance, while a Finnish participant claims that being diagnosed with HIV gave her the boost to do something with her life instead of just hanging around doing nothing; her Nigerian counterpart claims that it makes her go extra miles to accomplish extraordinary things. Furthermore, though HIV related illnesses ordinarily should negatively influence the productivity of PLWH (WHO 2002), with the use of medications, the participants have been well and productive, and may remain so for a long time (WHO 2010b). As such, unlike individuals with other chronic illnesses, most of the participants have the hope that they will remain financially independent for a long time (Koopman et al. 2000). This finding refutes the age long conception that testing positive to HIV ends an individual`s financial independence and dreams.

Therefore, the fear that testing positive is the beginning of the end of one`s chances to be productive, or a reason for giving up one`s responsibilities as a Finnish participant thought prior to her being diagnosed with the disease, is uncalled for. So instead of sacking PLWH, more of them should be hired so as to distract their minds from the disease which if left unchecked may worsen their situation. Apart from that, working will enable them to remain financially independence; without which in Finland could mean more reliance on the overstretched social insurance (KELA) and other social welfares (Aaltonen, Arsalo and Sinkkonen 2002), and in Nigeria where social security barely exist, it could mean increased poverty and crime. This outcome therefore refutes the Kluuvi Service Centre`s annual report which shows that many of their HIV/AIDS clients are highly dependent (Ibid). Perhaps their high dependence is due to other factors besides living with HIV/AIDS.

**Finding a career in educating people about HIV/AIDS:** It may sound surprising that living with HIV may not just increase an individual`s chances of finding a job, but also gives an opportunity to build a career in educating people about HIV/AIDS. Two of the Nigerian participants are very please for being given such opportunity. One of them shortly after testing positive in 2004 volunteered for a HIV/AIDS organisation`s AIDS Online services, TV series, and live radio programmes where she repeatedly gave HIV/AIDS education after receiving some trainings. Now she works with a HIV/AIDS organisation which has given her the privilege to meet highly placed individual of which ordinarily she would not have had access to. But to make concrete her chances of upholding the career of educating people about HIV/AIDS, she has abandoned her degree in Mechanical Engineering and return to school where she is now studying Sociology. The other who is in her final year has recently completed the training she need for a career in educating people about HIV/AIDS, and will soon zoom off to Osun State where she has been posted.

Another Nigerian participant similarly said that she regularly goes to counsel others at a screening centre in Lagos where she was diagnosed HIV-positive during her antenatal care. What she does at each visit is to go with a picture of hers taken before her positive diagnosis in 2004 as a proof that her health has remained intact. Then once she sees someone crying after a HIV-positive result, she will counsel the individual. In addition, by comparing the picture and her present look she will attempt to convince the individuals that the disease is not a death sentence. Going by this outcome, it seems that while the Nigerian participants are willing to be directly involved in the public crusade against HIV/AIDS ignorance if mobilised, their Finnish counterparts seems not ready for a career in educating the Finnish public; they believe that accepting such responsibility may be tantamount to making public their HIV-positive status which unlike their Nigerian counterparts they are not prepared to publicise. It is therefore essential for at least a HIV-positive Finn to consider breaking the spell because that may change the mind of others.

Particularly in Nigeria, this line of career is essential due to the need to tackle her HIV/AIDS`s ignorance. For instance as shown in chapter four one of the Nigerian participants prior to her HIV-positive diagnosis in 2000, had never heard about the disease. As strange as it may sound; it is not unusual because even in Bangladesh only about one in every five married women have heard about AIDS (UN Women 2011b), but this Nigerian participant`s case is baffling because the rampancy of the disease in Nigeria should not have given room for such ignorance. More also this participant is somewhat educated and lived in Lagos [the former capital of Nigeria]. However, that is a foretaste of how much many Nigerians are left behind as far as having a clear understanding of HIV/AIDS is concerned; especially in the rural communities. Furthermore, the scary images created by the media in the early 1980s (Clarke 2004) have continued to make many to panic, and that also deserves tackling; and it takes HIV-positive individuals like the above two to meaningfully contribute to wiping such image away (Paxton 2002), and at the same time educate individuals about the true dangers of unprotected sex (WHO 2002). They also stand in the best position to counsel PLWHA on what they must do to recover their health, and also the lifestyles they must abide by to remain healthy (Nedley 2011).

So while it seem things about HIV/AIDS are getting better, the need for individuals (especially PLWHA) to take fulltime job in educating people (especially Nigerians) about HIV/AIDS remains high due to her diversity and population. Then despite all the odds pertaining fears of being stigmatised or discriminated, PLWHA in Finland, Nigerian, and elsewhere should imitate the examples of the above Nigerian participants; for by giving people opportunity for becoming better informed, HIV/AIDS`s stigmatisation and discrimination which are PLWHA`s greatest challenge may become further minimised. So Government, Non-Governmental Organisations (NGOs) and all those on whose shoulders fall the duty of motivating and mobilising such interest and action should do so, so that in the next few decades, most of HIV/AIDS wrongful negative images in the minds of many would have completely disappeared, and attitudes towards PLWHA improved, so that instead of the persisting HIV/AIDS` secrecy, the disease could be discussed publicly.

**Hope for better days:** All the participants demonstrated strong hope for a bright future. The ones still studying have the hope of graduating and begin their working life which will guarantee their financial independence. The two single Finns have the hope that someday soon their dreams of finding life partners will be fulfilled. The participants also expressed the hope that HIV medications whose side-effects have been decreasing will continue, and since 10 or 15 years ago there were no sound HIV medications, and now there are very effective ones, they believe that 10 or 15 years in the future the medications will further get better. They are even looking forward to the long expected HIV/AIDS cure in their lifetime.

The participants` hopefulness pays because in hope is imbedded the power to endure difficulties with the expectation that tomorrow will be better. Throughout human history, hope has been very instrumental for coping with difficult times and situations. So, since living with HIV is difficult to endure, the role of hope in shaping the participants` positive state of mind cannot be overemphasized. This experience is consistent with what we already know; for instance, Kelly (2007) acknowledged that hope has proven to be an important resource for responding positively to HIV/AIDS. So in demonstrating true concern for this group of individuals, it is essential that we continue to introduce to them things that give hope, and channel them in strengthening manners as we look forward to the discovery of a permanent.

All of the key findings in this category affirm that in deed as some HIV/AIDS recent studies suggest, living with HIV is somewhat beneficial education-wise, health-wise (emotional/ mental, physical, and social), and also productivity and future goals-wise. Table five below shows the sub-categories and themes under which the key findings on the positive impacts of living with HIV are discussed. The table also shows that the social health benefits out numbers others.

**Table 5.** Positive impacts of living with HIV

| Num. | Education-wise impacts | Impacts on emotional/ mental health | Impacts on physical health | Impacts on social health | Impacts on productivity and future goal |
|---|---|---|---|---|---|
| 1 | Improvement of HIV/AIDS understandings (early discovery of positive status) | There are still chances of falling in love | Health and life restorer (cry cry cry) | Return of marriage fidelity | Finding a career in educating people about HIV/AIDS |
| 2 | Acquisition of power | HIV-negative husbands and children | Healthier than before | A test for true love | Working and remaining financially independent |

| | | | | | |
|---|---|---|---|---|---|
| **3** | Increased zeal for academic pursuits (recovering from lousiness) | | Free regular check-ups and medications | Steady relationship (a more permanent relationship, strengthening of family) | Hope for better days |
| **4** | | | | Drawn closer to God | |
| **6** | | | | Support group meetings | |
| **7** | | | | Disclosure is beneficial (it keeps hope alive) | |

## 5.3 Positive lifestyle changes due to HIV-positive status

The study outcomes discussed in this category ideally should be part of the preceding one (Positive Impacts of Living with HIV), but I singled them out specifically because they are the transformative positive changes the disease compelled the participants to make. They are primarily obtained from category 7 of chapter four. Some of the findings also agree with few recent studies which argue that despite the fact that living with HIV has numerous negative effects, the condition also handsomely benefits individuals` education-wise, health-wise (emotional/ mental, physical, and social), and also productivity and future goals-wise. Some of the findings discussed here somehow completely refute what we already know about living with HIV.

### 5.3.1 Education-related positive transformations

This sub-category discusses how living with HIV transforms an individual into a better cook, and as well motivates interest for promoting the use of condoms (even in settings that kick against it), and also the promotion of voluntary HIV screening.

**Becoming a better cook:** It is becoming a norm for many to ingest anything that come on their way (especially palatable ones) without sufficient consideration of the nutritional values and health consequences of each. This era seems to be becoming increasingly characterised with rampant fast food joints. So unlike in those days when in Nigerian, knowing how to cook is one of the major yardsticks for measuring a lady`s preparedness for marriage, it seems many ladies nowadays do not know how to cook nor find pleasure in entering the kitchen. But even in this changed age, a Nigerian participant who did not know how to cook nor cared about learning it became transformed after testing positive to HIV. This change was primarily because she became aware and compelled by the fact that her HIV-positive body is now frail and in constantly need for nourishment through healthy meals which she cannot get from her usual fast food joints. For this participant and many others, living with HIV gives the opportunity of learning how to cock. So while this participant has been favoured

by the new lifestyle now she is still single, that may also greatly contribute to the bonding of her future nuclear family.

Furthermore, though the problem with eating junks in Finland may not be that high because restaurants are well regulated, but with the presence of fast food joints here and there, the risks of such still remains, and that places the health conscious PLWHA who learned how to cock and began to eat healthier after their positive diagnoses (NordPol 2007) at advantage grounds. FAO (2002) argues that, the PLWHA are often propelled to eat healthfully because it sustains their strength and body weight, replaces lost vitamins and minerals, and improves the ability of their immune system to fight opportunistic diseases. Therefore, in as much as it is essential to eat food that are appetising, appetite must not be the ultimate determinant of what we eat (Liu 2004, Gallus et al 2005, Campbell and Campbell 2006, Craig 2009). Studies show that the taste bud can even be retrained (Greger 2013).

**Promotion of condoms and HIV screening:** Undoubtedly, the best option for HIV/AIDS and STIs prevention is abstinence for the singles and fidelity for the married, but as the world gets increasingly sexualised the second best option is to use condoms as argued by some of the participants. In the light of this fact, the participants are seriously concerned about taming the spread of STIs including HIV/AIDS (WHO 2002) and as such promote condoms. Some even advocate that it should be made freely available for all. As they also demonstrated, such promotion does not go down well with religious leaders especially in Africa because they believe it mean promoting promiscuous sex. But in the midst of this dilemma (condoms promotion to prevent STIs or not promoting it to avoid promoting promiscuous sex) what is the better option? The first option seems better, but the environment for its promotion must be well considered (children free environment). In addition, these participants do not just promote condoms use but also use them. Apart from a Nigerian participant who said she occasionally skips using it especially when they want to make babies, all the other participants use condoms constantly.

Furthermore, they also promote HIV screening. While one of the Nigerian participants due to keeping wrong company was going for the screening every six months until she tested positive, her Finnish counterpart is even surprised that her friends have not gone for the screening despite knowing what happened to her. The screening is mostly free, but the fear of testing positive is not allowing many to go for it; while as it pays to discover positive status early (Porter, Wall and Evans 1993, WHO 2010b).

### 5.3.2 Emotional/ mental health-related positive transformations

This sub-category discusses the transformation of the participants into accepting their positive status, their realisation that life has no duplicate and should be lived well, and the less stress lifestyle they adapted after testing HIV-positive.

**Acceptance of positive status:** As earlier established, due to identity crisis, HIV/AIDS acceptance is very difficult which is why it takes being transformed

to do so. As one of the Nigerian participants argues, some will even run to churches in search for the miracle that will reverse their positive status, nevertheless, the participants of this study accepted their positive status in good faith, though it was not easy. The struggle is well demonstrated in Anderson and Spencer (2002, 1347–8) where a participant at first said, *"I hate that word. I`m still trying to accept it, I think. Yes, I am trying to accept it",* and latter he said, *"It`s finally sinking in that I do have it and I`m starting to feel lousy about it"*. So though the acceptance is difficult, it seems to brings in new perspectives into one`s life.

**Realising that life has no duplicate:** Consistently many individuals abuse their bodies and endanger their health because they presume that it does not really matter. However, testing positive to HIV (like being diagnosed with other chronic diseases) somehow triggers such attention as it happened to the participants of this study. After testing HIV-positive the participants realised that they have only this one life which should be well lived, and that made them to begin to appreciate life more than before. So unlike some healthy individuals who commit suicide for no good reason, the participants now love to live rather than to die. To uphold this new goal, they have started to take more care of themselves (health-wise) unprecedentedly because they have realised that PLWH can enhance their quality of life and control the progression of the disease through caring for themselves (Anderson and Spencer 2002). So it seems being diagnosed with HIV does not just give the opportunity to acquire essential health knowledge, but also gives the needed motivation to implement them. It is true that sometimes individuals get bored and begin to indulge in what they know is stupid and self-destructive, and then along the way it becomes a norm which is how addictions mostly work. So after being hooked, some individuals may continue to destroy their health not for lack of knowledge, but for the lack of will power to do otherwise. Maybe as neurological studies advance, we will know exactly what happen to the brain chemistry that leads to sudden change of mind and then action which completely reverse an individual after a HIV-positive diagnosis, but the point is that for many individuals, being diagnosed with HIV (as demonstrated by the participants of this study) strengthens zeal to change from unhealthy to healthy lifestyles.

**Less stress:** Although some level of stress is essential for the normal functioning of the body, but in an increasingly busy world where people are running here and there in efforts to meet their thousand and one needs or to accumulate wealth, many unknowingly over step their boundary and as such overstress themselves which may be why stress is increasingly becoming a major health problem. But though physical stress is having its toll on individuals who abuse their bodies by pushing more than their capacities, it seems emotional stress is more harmful. It is unfortunately true that university students` academic stresses coupled with the physical ones (especially among those who are also working) may amount to excess stress. Nevertheless, to the participants of this study, living with HIV has given them the opportunity to know their limits and also the willingness to take life easy. So they no longer push themselves to extremes,

but take breaks and retreats from activities as regular as they feel is necessary; this is worth emulating by all.

### 5.3.3 Physical health-related positive transformations

This sub-category discusses the participants` transformation into living positively and healthfully, through replacing some odd habits with better lifestyles, through self-support, and through choosing beauty that comes from eating right rather than from make-ups.

**Healthful and positive living:** In today`s world where everything seems to be happening fast, many are very busy pursuing wealth and most times do not pulse to consider the dangers of their environment and their kind of work on their health. But living with a chronic disease like HIV seems to help in slowing people down to do some reflections on their life and pursuits. A Finnish participant received this privilege after her positive diagnosis; and reflecting upon her life has made her realise that she need to take life easy because working very hard and making a lot of money is not everything. So to her, the desire to acquire abundant wealth (which is increasingly destroying values) has disappeared, she just hopes to find a job that will contribute to saving the world after graduation. If many will imitate her, this world may somehow become a better place.

Furthermore, since PLWHA are at increased risk of clinical malaria, severe illness, hospitalisation, and death (NMFS 2011), a Nigerian participant who is prone to malaria due to her AA genotype argues that her being diagnosed HIV-positive has made her to begin to pay additional attention to her surroundings in order to avoid mosquito bites which results to malaria fever. Though Nigerian environment makes it very tough to completely avoid mosquito bites; nevertheless, she claims that she does everything within her reach to attain the goal including constantly sleeping under mosquito treated net. She also claims that she tries as much as possible to avoid opportunistic infections. Her Nigerian fellow taking the caution a step further said, she has not gone to the salon to do her hair since 2004 she tested positive to HIV, but suppose she chooses to do so tomorrow, she will go with her own set of tools. These responses reveal that being diagnosed with HIV somehow transform an individual and makes living more appealing and interesting.

**New lifestyles in place of old habits:** As far as becoming health conscious is concerned, testing HIV-positive served as a wake-up call for the participants of this study. Haven realised that their bodies require more than the care they have always given to it, they now attempt to eat healthier, and engage in physical exercise regularly (although it was inconveniencing at the beginning). Particularly, unlike before, they have started to eat fruits and vegetables on regular bases. They have also started to drink a lot of water (Davy et al. 2008, Kempton et al. 2010), began to spend quality time relaxing, avoid things that hinder sleep, deceased from taking soft drinks, and avoid sharing shape objects. They also claim that instead of being pushed around by trends, they have started decide

what is ideal by themselves. Most of the healthy lifestyles the participants claimed to have recently embraced are consistent with Nedley (2011) list of ten common healthy attributes National Geographic found in the blue zones. For instance, as a part of the participants` new eating habits, they now eat a lot of fruits and vegetables daily of which studies are increasingly showing that it is the ideal way to live. Even Hardinge (2008) suggests six to eight servings of fruits and vegetables per day in order to minimise our risk of cancer and other chronic diseases. This shows that the participants have realised that whether vegetarian or not, eating a lot of fruits and vegetables is good for them (Liu 2003, NAP 2003).

Furthermore, they chose to involve themselves in different kinds of physical exercise probably because they have realised that physical exercise is very beneficial to health (Wen 2011), and failure to partake of it is suicidal. For instance, while Hardinge (2008) argues that though we do not yet know if exercise reduces LDL (the bad cholesterol), it increases HDL (the good cholesterol) which reduces the risk of heart attack – the world`s consistent number one killer! He further argues that muscular strength, abdominal strength, grip strength, as measurements, are very effective in predicting one`s ability to be functional 25 years into the future. Similarly, Wen et al. (2011) revealed that those who exercised for an average of 92 minutes per week or 15 minutes per day have a 14% reduced risk of all-cause of mortality, while individuals who are inactive have a 17% increased risk of mortality.

In addition, despite the inconvenience of frequent urination, the participants now drink a lot of water (Gopinathan, Pichan and Sharma 1988,) probably because they have realised that greater proportion of human body is water (Batmanghelidj 2013) and we are healthier when we have plenty of it (Nedley 2011), because for the body to function properly, excreted and lost water need to be regularly replaced. Chan, Knutsen, Blix, Lee and Fraser (2002) shows that increasing water intake up to 5 glasses a day decrease the chances of dying from heart attack up to 54%. Some of the participants of this study also claim to be avoiding soft drinks of which the same study suggests is worse than dehydration itself.

Furthermore, some of the participants claimed to be going for recreation and relaxing regularly which normally is very difficult for many due to human business; nevertheless, they now do it because they know its numerous health benefits. Then unlike many who frequently use caffeine and other sleep deprivation substances, some of the participants now avoid them. But what I see to be most appealing in the now attributes is ‘will power’; which has enabled them to start deciding for themselves what is good instead of being pushed around by common unhealthy lifestyles around them. In fact, that seems to be the engine propelling the positive lifestyle changes they have been making.

**Self-support:** While HIV/AIDS related stigma and discrimination need to be collectively fought because it leads to identity crises, isolation, loneliness, low self-esteem and lack of interest to fight back against the disease (Valdiserri 2002), PLWHA ought to individually support themselves in addition to other supports they receive. The participants of this study were transformed by the

disease to greatly support themselves, and that has been benefiting them a lot. So in a world full of complain of what the government is not doing for the people, if others will emulate supporting themselves we will begin to see less complain.

**Looking good without a make-up:** In today`s market there are make-ups of all kinds, and some are even beyond the reach of an average person. Many seem to have become so used to particular make-up products and may hardly do without them. So it is unfortunate that hundreds of thousands of people wear different chemical compounds in the name of make-up without being concern about the impacts of the chemicals on their health (Yle July 2011b). Although from some points of view make-ups may have some advantage, but the rate at which they are being used seems overwhelmingly high and dangerous to health. In addition, other forms of body enhancement have also emerged. Individuals now tattoo and piece different parts of their bodies because they see it as the 'new normal'. For some it begins with a little tattoo, and before they know it, there is almost no more space on their body to inscribe the one they have lately discovered to be the best. The trend is in full swing and the trend is in line with Nedley (2011) which argues that we cannot have enough of what we do not need. So why do we waste our time, money, energy, and so forth on what we will later regret? So in the midst of these unnecessary search for beauty when the lasting one comes from inside (as a result of good nutrition and well cared body), a Nigerian participant now no longer spend fortunes on buying make-ups because the new healthy lifestyles that being diagnosed with HIV has led her to, now makes her to still look beautiful even without a make-up.

### 5.3.4 Social health-related positive transformations

This sub-category discusses two positive social health transformations which are becoming a better person and exercising self-control.

**Transformation into a better person:** As usual testing HIV-positive adds positive perspectives to life (Anderson and Spencer 2002), but for the participants of this study, it extends to changing them from wayward lifestyles (like unnecessary quarrelling) to becoming better persons (like being less judgemental, less selfish and helping others). As such, they now quarrel much less, judge others less because they have realised that there is not mush to be gained from such lifestyles. Instead they see helping others who are in greater need than they are as a kind of emotional healing approach which takes their minds away from themselves, the disease, and worrisome feelings. This is probably why one of the Finnish participants instead of worrying about her condition, she is concerned that while with medications and good healthcare services she is doing well, others with the same disease in less privileged countries are suffering and dying.

Another Finnish participant even pointed out that her HIV-positive friend who could not just sit back and watch HIV/AIDS devastate Malawi, moved there as a missionary and formed HIV-education group, and based on what she saw on ground, malnutrition is a much more health problem there than HIV, so

herself and the friend in Malawi are advocating that it should be tackled first. So if not for empathy for those whose conditions are more critical, the HIV-positive Finn would not have move to Malawi, and from the narrative it could easily be noticed that the importance of helping the Malawians whose conditions are worse than hers has to a large extent taken away from her mind the fact that she is also HIV-positive. As demonstrated thus far, helping others in greater need contributes greatly to taking away a HIV-positive individual`s mind from the virus, and also from other negative feelings. But because helping others out of 'agape love' is often seen from religious point of view, many who distaste religion try to disassociate themselves from such. But nevertheless, recent studies show that helping others is beneficial even to health (Nedley 2011, WHO 2013).

**Self-control:** One of the major challenges for some individuals (especially young people) is 'lack of self-control' over what seems appealing to them. It is unfortunate that many of the 'ready to eat' foods and drinks we buy from glossary stores are very high in sugar, salt, fat, and other ingredients that require limited consumption. So by eating and drinking them repeatedly because they taste good (like energy drinks) (Yle November 2012b), some have been hooked and now binges on them at the detriment of their health (BBC October 2008, BBC March 2011, Yle June 2012b, Yle August 2013b). A Finnish participant who confessed her affection for sweet things (BBC February 2008, Lustig 2009, Yle October 2013b) said ever since she tested HIV-positive, she has been trying very hard to eat less of them, and this is likely the same with other PLWHA who have been addicted to similar unhealthy food items. So for a national and international health challenge which legislations that includes increase in the cost of sugar and other sweet products (Yle October 2011) have not been able to solve in Finland, it seems testing positive to HIV is doing a lot in deterring people from such products.

Then though studies show that what has significantly reduced in the life of PLWHA in the Nordic countries is their alcohol consumption and not their cigarette smoking (NordPol 2007); the Finnish participants in this study claim that they have not just quitted smoking and drinking, but also partying probably because their new social environment consisting mainly HIV-positive health conscious individuals (group meetings) influenced her.

Furthermore, everywhere in the world, the human and economic costs of drinking are becoming huge (Yuan et al. 2004, BBC October 2011, Parkin 2011, Yle June 2013). For instance, many accidents occurred under the influence of alcohol (Yle June 2012c), and in order to control drunk driving, the Finnish and other governments spend a lot of money on testing if drivers` blood alcohol level exceed the legally allowed limit. So as unnoticeable as it may appear, living with HIV/AIDS which compelled some not to drink at all may have slightly contributed to reducing the cost of alcohol consumption. So supposing the disease is not highly discriminated and stigmatised as it is now, and the PLWHA in Finland choose to live in a municipality of their own, perhaps there would not be need to waste public resources testing the drivers in the municipality, while the municipality will still uphold zero drunk-related accidents. In

contrast to this, many Finns suggested in a recent Yle poll that legislations and increase in the price of alcohol beverages is not enough to mobilise the most wanted change (Yle July 2013). So since the knowledge of its negative impacts on health, legislations and increase in price have not made much difference in Finns` drinking habits; so in line with UNAIDS (2012: 5) which states that, *"50% of people living with HIV do not know their HIV status"*, perhaps if some of the individuals in limbo will go for screening and find out about their HIV-positive status, may be that will contribute its quarter in making this important difference in Finns excess drinking habit.

### 5.3.5 Productivity and future goals-related positive transformations

This sub-category discusses two positive transformations in the participants of this study; their planning and becoming time conscious, and their advocacy for the employment of standby HIV-positive counsellors at HIV diagnostic centres.

**Planning and becoming time conscious:** It seems obvious that some individuals have no plan for their life, nor goals and sense of purpose, and thus are pushed about by wind of circumstances. When due to its importance, planning or having sense of purpose is one the ten attributes shared by the inhabitants of the blue zones (health and longevity hotspots) (Buettner 2008). Even among the individuals who know that they need to plan for themselves and their posterity, some still get carried away, and when sudden death occurs, those who are left behind bear the consequences of such lifestyle. But HIV/AIDS being a constant reminder of inevitable death has made one of the Nigerian participants to see the need to start planning her life so that in case anything happen to her unexpectedly, her children will not have much to suffer for. This outcome shows that HIV-positive related transformations help individuals in eliminating aimlessness by triggering the need to plan in order to bit troubles that may arise as a result of the individual`s sudden death.

Furthermore, by taking their medications at a given time mornings and evenings, some of the participants claimed that their body clocks have now been set in a way that they are very time conscious. Of course this is a good development especially for the Nigerian participants because in Nigeria (like many developing countries) where people hardly keep to time which gave birth to the phrase – 'African time'. The general lack of time consciousness is one of the greatest setbacks to productivity. So going by this outcome, it seems the disease has given the PLWHA in Nigerian the privilege to somehow overcome the habit of time unconsciousness. Similarly, Nedley (2011) argues that, regular schedule is beneficial even to health. So, in this sense, it seems living with HIV somewhat pays.

**Advocating for a standby HIV-positive counselors:** It has been well established that if a person living with HIV gives sex education (especially to students), fear and prejudice will be decreased, and the spirit of constant protective behaviour will be reinforced (Paxton 2002). But beyond that many HIV/AIDS organisations have employed as part of their staff PLWHA because they have

seen that the need for their service is huge. But realising the importance of being deeply involved in counseling the newly diagnosed HIV-positive individuals and couples at health centres, the Nigerian participants said they are now advocating for the employment of standby HIV-positive staff at such centres who will immediately counsel the newly diagnosed persons with the disclosure of their own positive status so as to minimise the effects of the initial shock of being pronounced HIV-positive. This advocacy sounds logical because it takes who have passed through it to know what it means to be pronounced HIV-positive, and also because it takes calming down the initial shocks for coping with the disease to be initiated. Then though the Finnish participants seem not to be advocating for such, it may also be to their interest.

All of these facts also affirm that in deed as some recent studies suggest, living with HIV is somewhat beneficial because education-wise, health-wise (emotional/ mental, physical, and social health), and productivity and future goals-wise it has transformed the life of the participants of this study. In addition, table six below outlines the sub-categories and themes under which the key findings on the HIV related positive transformations are discussed. The table also shows that the physical health, emotional/mental health, education-wise transformations outnumbered the other two.

**Table 6.** Positive lifestyle changes due to HIV-positive status.

| | **Education-related positive changes** | **Mental/ emotional health-related positive changes** | **Physical health-related positive changes** | **Social health-related positive changes** | **Productivity and future goals-related positive changes** |
|---|---|---|---|---|---|
| **1** | Becoming a better cook | Acceptance of positive status | Healthful and positive living | Transformation into a better person (helping others) | Planning & becoming time conscious |
| **2** | Promotion of condoms | Realising that life has no duplicate (love to live) | New lifestyles in place of old habits | Self-control | Advocating for HIV-positive counselors |
| **3** | Promotion HIV screening | Less stress | Self-support | | |
| **4** | | | Looking good without a make-up | | |

## 5.4 Outstanding surprises from research outcomes

There are many surprises from of this study`s outcomes, but some of the most outstanding ones are outlined here. It is surprising:

a) To discover that the low number of PLWHA in Finland hurt than it helps the people.
b) To find out that Nigerians living with HIV are more positive about their condition than their Finnish counterparts. Perhaps the large number of PLWHA in Nigerian might have contributed to that because one of the Nigerian participants said 'their visiting one another helps in convincing the people within a given neighbourhood that they are not alone'.
c) That a large number of PLWHA in Nigeria now publicly declare their HIV-positive status without the fear of being stigmatised or discriminated despite the fact that the Nigerian society is structured in a way that such individuals may be easily identified.
d) To learn about that increasing number of HIV-negative individuals in Nigerian knowingly and willingly getting married to HIV-positive partners without the usual scariness of getting infected.
e) To find out that the chances of mother-to-child HIV infections in Nigeria have drastically reduced.
f) That a Nigerian participant who claimed to had remained a virgin until she got married tested HIV-positive while her husband repeatedly tested HIV-negative, which proofs that it is not all the PLWHA that are promiscuous.

All these surprises contribute to cementing the fact that HIV/AIDS conceptions are dynamic and not static. In fact during the interviews, one of the Nigerian participants spotted my outdated views and said, "...it seems you left Nigeria long time ago!"

## 5.5 Research limitations

As a phenomenographical research work, this study followed structured and socially approved procedures. The study is reliable because if the same study is re-conducted by different researchers using the same methods, the outcomes would likely be the same. In addition, that the participants were interviewed long enough until there was no more new ideas, and concept maps and thematic tables were used at the end of each category in chapter four and appendix respectively to show the same results add to the reliability of the study. However, there are aspects of this study which limits its validity. First, the number of those who participated in this study is few (seven – three Finns and four Nigerians). They are also literates (tertiary students) who live in cities. Above all, they are all ladies living with HIV only (not AIDS), as such I could not examine the conceptions on the disease from men`s point of view, and that of those living with AIDS. So perhaps if the same study is conducted using larger number of participants of both genders who are both literates and illiterates and are also living with AIDS in rural and urban settings, the outcomes might be slightly different; which perhaps may be a more balanced conceptions on the meanings of living with HIV/AIDS.

Furthermore, that one of the Nigerian participant is studying in a teachers` training college, and that two of the participants (a Finn and a Nigerian) have

already graduated may slightly influence the validity or representation of the participants as university students. This is why in the preceding chapters [especially in the results] I also used tertiary students instead of just university students. In addition, that only four of the participants (two apiece) tested HIV-positive before their university enrolments may have affected the capacity of the study to find out the true effects of the disease on university enrolment as in the case of the Nigerian lady in chapter one who contributed to motivating this study.

Then though this is also a comparative study, it was somewhat bent towards Finland than Nigeria (especially the literature review). This may probably be because there are more relevant literatures on some of the subject of interest in Finland who's Research and Development (R&D) investment per GDP is among the highest in the world (OECD 2011). This slight imbalance might have also been influenced by the fact that my school of study is in Finland. Nevertheless, amid the limitations, the main goal of the study (to better HIV/AIDS understandings) seems to have been met. In addition, though for ethical reasons throughout the process of this study efforts were made to ensure that the study participants are not hurt (including the withholding of name of places they were), that seems not to have had much effect on the study outcomes.

## 5.6 Recommendation for further studies

Due to the above limitations of this study, I will first recommend a similar study using larger number of participants of mixed gender who are also illiterates and live in rural settings too. Perhaps that will reveal what is missing out from this study. In addition, I had expected that the Nigerian participants would have been more negative about their conditions than their Finnish counterparts, but unexpectedly the reverse is the case. So I will also recommend a study investigating the factors responsible for their overwhelming positive attitudes despite the rampancy of poverty and other challenges in Nigeria.

## 5.7 Main implications of the study

Based on what we already know, besides being an infectious disease that is often linked to promiscuous and deviant lifestyles (Clarke 2004), many are exceptionally afraid of HIV/AIDS because they are still holding on to its myths, fables, or out dated scratch on the surface deposited in their minds since early 1980s. In addition, the exceptional fear is also because about 50% of those living with HIV do not know their HIV status (UNAIDS 2012), so many who have not gone for HIV/AIDS screening are not sure if their past carefree lifestyles have made them infected with the disease, as such, at each time the disease is mentioned, they are frightened even to their marrows. Therefore, this study which is aimed at bettering HIV/AIDS understandings has comprehensively and explicitly explored the meanings of living with the disease through examining and comparing the conceptions of HIV-positive students in two diverse countries in search for the education-wise, health-wise (emotional/ mental, physical, and social), and productivity and future goals-wise impacts of the disease in

order to give readers the opportunity to better understand the disease and the PLWHA, and thus positively change their attitudes towards the disease and also toward the PLWHA. The chances of this study to positively transform readers seems high because as Nelson Mandela argues, education is the most powerful weapon with which the world could be changed (Bi-Botti 2009), and acquiring better understandings on HIV/AIDS through those living with it may not be an exception.

Specifically, the study will enable HIV-positive readers to further get acquainted with the disease through the conceptions of their fellows which will enable them to better mitigate the impacts of the disease. As well, since the study provided insights on the meanings of living with HIV in both Finland and Nigeria, the participants could learn from each other`s experiences as explicitly and comprehensively compared in chapter four to better mitigate the impacts of the disease on them. Then since knowledge is power (Vickers 1992), the study will enable readers within another group of the main audience of this study (students in limbo) to minimise their fear of the disease and thus become encourage to go for HIV screening, because after reading the study they will become better equipped to make decisions based on facts instead of myths and fables. The study outcomes may better enable HIV/AIDS organisations to tailor the implementation of their programmes toward meeting the needs of their subjects of which this study explicitly explored. School authorities by reading this study may further see the need to make school environment more HIV friendly. In addition, local, national, and international authorities may be influenced by the findings of this study to improve their HIV/AIDS policies.

Before I stated the study, I was just like every other novice without enough insight on HIV/AIDS, nor with clear understanding as to what extent it affects PLWHA, but now I feel fulfilled that this study gave me the opportunity to broadly explore the disease to the point that many of its details are now on my fingertips. Again during this study I had the opportunity to for the first time meet and conversed one-on-one with HIV-positive individuals, and instead of meeting the kind of individuals I have always pitied for (as many still do), I saw healthy persons who are not just well informed about positive and healthy living, but individuals who do not take for granted (like many others) health matters, but have made healthful living their daily routine. So being challenged by what I discovered through this study; I am now much more health conscious, and that has greatly improved my health. So, I believe that others who will read this study will be transformed too.

## 5.8 Conclusion

Seeing that one of the major challenges with HIV/AIDS is that its meanings are highly subjectivity due to the lack of adequate HIV/AIDS understandings mostly because beside the rampancy of its myths and fables, facts about HIV/AIDS are scattered here and there while the disease continues to have its tolls on students who are most vulnerable to it. So as purposed in chapter one, the goal of this study is to better HIV/AIDS understandings through exploring the conceptions of HIV-positive university students in Finland and Nigeria in search for

the negative and positive impacts of the disease on education, health (emotional/ mental health, physical health, and social health), productivity, and future goals, with the plan of primarily reaching two group of audience – HIV-positive students and students in limbo. The plan is that the HIV-positive students will use the bettered HIV/AIDS understandings acquired through this study to further mitigate the impacts of the disease on them, while the students in limbo will use the knowledge acquired through this study to eliminated HIV/AIDS myths and fables and thus have their fears of the disease minimised which will encourage them to go for HIV screening to know their true HIV/AIDS status. The overall aim of the study is to use its findings as a platform to promote positive and healthful living to all. So the study using phenomenographic approach was able to describe not HIV/AIDS itself but the conceptions of the Finnish and Nigerian students on the disease based on their conceptual thoughts and immediate experiences with the disease, and thus answered my research questions.

Although based on what we already know, the negative impacts of HIV are much more visible; nevertheless, this study shows that there are increasing numbers of positive ones. As the study reveals, living with HIV (not AIDS) increases HIV/AIDS understandings (which influences individuals` conceptions and possibly behavioural changes towards the disease and PLWHA), it offers privilege for regular free medical check-ups (which enables early detection of other formidable and deadly diseases) and medications, it broadens health knowledge, it compels positive and healthy lifestyles (which increases the opportunity for good health and longevity), it enhances motivation for academic pursuits, it motivates zeal for productivity (which enables financial independence and distracts thinking about the virus), and as such does not really thwarted goals. Furthermore, it motivates deeper health consciousness, it encourages positive attitudes, it transforms one into better person, it makes one a better cook, it ascribes better citizenship attributes, it opens doors of opportunity to build a career on educating people about HIV/AIDS, it restores health, it enables looking good without a make-up, it promotes fidelity, it confirms true friends, it enables steady relationships, it increases number of friends, it gives hope, it encourages planning and becoming time conscious, it promotes self-control, it encourages less stress lifestyle, it increases godliness, and so forth. So in view of all these benefits, it seems being diagnosed HIV-positive does more good than it hurts – especially to health.

The outcomes also show that except for the participants` positive mindedness and healthy living transformations, there seems to be no wide gap between the recent predominant HIV/AIDS conceptions and the conceptions of HIV-positive university students. Then the comparison of the two groups reveals that there is also no wide gap between the Finnish and Nigerian participants` conceptions on the disease. Nevertheless, it seems that while the Finnish participants are slightly better informed about HIV/AIDS, their Nigerian counterparts seem to be more open and positive about their conditions, and as such HIV-related guilt, suicide thoughts and attempts were exclusive to the Finnish participants.

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# APPENDIX I

Appendixes I to VII contain tables 7 to 32 which show the comparison between the Finnish and Nigerian participants` conceptions backed with facts from literature.

**Table 7.** A comparative illustration of the initial knowledge of participants

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| Something that Happens in Africa/ Not Made for Me | So I was saying like many Finnish people it doesn`t affect their lives. I have to admit that I thought is something that happen maybe in Africa and have nothing to do with my life (sh0485ff) | Before I know my status I think HIV was not made for me, I think I don't have any business with it (ht0484fn) | The failure of many to see themselves within the high-risk group, and commit to safe sex facilitate the spread of HIV (Durojaiye 2011) |
| Death Sentence/ Deadly Disease | Death sentence (ms9367ff). In the beginning I really thought that am going to die soon, younger, or something (sh0485ff) | When I was still young, I use to hear about HIV, I thought it was a deadly disease, I even thought HIV is AIDS, I never believe there is difference between AIDS and HIV (as0481fn) | A 48 year old participant in Anderson & Spencer (2002, 1344) who sees AIDS as a life devourer says: *"I feel I have no life. It has change my whole perspective"* . |
| Gays Disease | When I was about 17, the first case came public, he was that actor Rock Hudson. We just laughed about aids and thought it was for gays only. Gay disease (ms9367ff) | | In the Finnish context, the primary framework for understanding AIDS is gay plague (Clarke 2004) |
| Something Dirty | Well I thought it was somehow like you know dirty, and the people with the disease are dirty, and I considered myself very dirty as well when I first got it (sn9975ff), Social recluse (ms9367ff) | | In the 1990s, many Finns believed that HIV/AIDS is chiefly borne and distributed by migrants; one vocal camp believed that strong managerial responses that include quarantine was necessary (Clarke 2004). There were also talks on sending infected people to unused leper colonies (Clarke 2002) |

| | | | |
|---|---|---|---|
| Something Scary | I was under 10 years old and maybe really scary thing (sn9975ff), Kaposi's sarkoma in the face (ms9367ff) | | In Anderson & Spencer (2002, 1344), a woman pictured AIDS as *"Pain from head to toe, no hair, 75 pounds, can't move, can't eat, lonely and scared. Family loving you and you can't love them back."* |
| An Opportunity to Give-up All Responsibilities | I thought well if I someday get HIV, I just give-up my responsibility and everything and just keep doing [drugs], but it was something scary (sn9975ff) | | The informants of Anderson & Spencer (2002) envisioned AIDS as people who are reduced to skin and bones, extremely weak, in pain, losing their minds, and lying in bed waiting for the end |
| No Idea | | I was so innocent; I didn't even know what it is, I didn't know what it is (aw0071fn) | Only about one in every five married women in Bangladesh have heard of AIDS (UN Women 2011b) |

**Table 8.** Present understandings of participants on HIV/AIDS

| **Themes** | **Finnish Conceptions** | **Nigerian Conceptions** | **Results of earlier research** |
|---|---|---|---|
| Not Necessarily a Death Sentence | ...now I know I won`t die of it because I have medication if I don`t start using drugs again I will probably die of old age (sn9975ff) | Initially, anyone that hears HIV just believe it mean "death sentence", in no time this person is going to die. People`s perceptions about the disease is changing on a daily bases (tp0389fn). Actually, that (death sentence) was what came to my mind, and I was crying, but it was through counselling I got better... I came to conclusion (that is not a death sentence) when I have seen, by the time they started giving me treatment, there was improvement (aw0071fn) | One participant in Anderson & Spencer (2002) perceived AIDS as a skeleton crying |

| | | | |
|---|---|---|---|
| Not Necessarily AIDS | Hiv is not aid, nor does it lead to aids necessarily. Hiv can be blown into fully developed aids. They are differenrt stages of the same disease Well nowadays if I take my medicine treat myself right maybe I`ll never maybe get AIDS (ms9367ff). So nowadays is not usually like in the 80s you have HIV you get AIDS and die (sh0485ff). | it was when I came across it [when I tested positive] I know that is different from AIDS. Is when HIV is not been care of before it leads to AIDS (as0481fn) | According to the participants in Anderson & Spencer (2002), one still has the chance to fight while it is still HIV, but once AIDS begin to appear in one`s record, the person has bought a ticket [to death]. |
| Not that Contagious | Now that I know that because of the medication I know that am not you know dangerous (sn9975ff) | And if anyone is said to be HIV positive, they believe that this person, if you go near this person you will be infected. But now, the perception is changing on a daily bases, in the sense that people are actually getting more knowledge on what it is all about, how it can be contracted, how it cannot be contracted you know. HIV to me with the level of awareness now, people are not as scared as they use to be in the past. So is changing on a daily day to day bases, is changing and that really has helped improve our conception (tp0389fn) | More than 50% of Nigerians say they cannot shake hand, hug or share the same toilet with PLWHA (Ogunjuyigbe, Adeyemi & Obiyan 2009). But recent studies suggest that male circumcision alone can reduce the risk of acquiring HIV though sex (WHO 2010b) |
| Just a Disease | I no longer think of it as a mortal disease. It is a cronic one, treatable one.... it is a chronic disease among other diseases. It no longer leads to premature death (ms9367ff) It can be like a chronic disease, a bit like diabetes that some people can treat it and manage to live with it, live as normal as possible ... (sh0485ff) | Is not something to me, is not something somebody will need to kill him or herself for. Is just like ordinary other diseases. Like people can manage hypertension, can manage diabetes, can manage other things, so also HIV (aw0071fn). And I think those that have diabetes they always take their drugs. When they are down they will go to the hospital, those that have hypertension they are on drugs, the drug helps them to manage it but it doesn't have cure! Like HIV it doesn't have cure but you can manage it with the drug ...it was then I say this is not a do or die matter (aw0071fn). I just see it as a condition (tp0389fn) | In Anderson & Spencer (2002, 1348) some participants made AIDS sound better by imaging it as a chronic disease like cancer or diabetes that only requires regular taking of medications. One of them says: *"At first I thought I was going to be all messed up, all dried up and looking weird and stuff like that, but I don't think of those things anymore. I just keep living life."* |

| | | | |
|---|---|---|---|
| No More as Something Dirty/ No More Fearful | Well I thought it was somehow like you know dirty, and the people with the disease are dirty, and I considered myself very dirty as well when I first got it, and that took a long time for me to get rid of that, you know just feeling of been dirty, but that has changed, I don`t think about it in that way (sn9975ff) | That was then, not any more (i.e. skeletal image). Is before, is that image that put fear into human – to people. That impression they gave that time. They just brought skeleton and everything, but now if you are walking you cannot know who is who. That impression then they created that is what has created that fear in people. (aw0071fn) | In the Finnish context, the primary framework for understanding AIDS is gay plague (Clarke 2004), but the trend is changing because heterosexuals are now more represented among PLWHA |
| Sure HIV Vaccine Uncertain | Well I don't know a lot about it, but I know is very hard to find it. The virus it`s, it changes so rapidly, and it look so different in people, people like have different strain of it, and also the strain you have is very, is a very intelligent virus, and also it hide in the cells that are not used so even if you get it away, if you get it away from the active cells in your body, is hiding in the not active ones. And I know that there has been some vaccination, there have been some research somewhere in Africa, and it has minimised the possibility of getting the disease 40% or something. I really think like safe sex and clean needles, needles protection proper, they are the best vaccination, 40% is not, I don't think before companies come with this 100% vaccination, maybe we should put more money on information and you know helping to stop it in other ways you know. | Vaccination? No I have not heard about it. (as0481fn) I have heard it but I don't know much about it. (ht0484fn) there are vaccines now that will help [control] the infection, like for instance I want to get married to – my partner is negative, that vaccine will help prevent my infecting him, of course I want to get pregnant (tp0389fn) | There is currently no vaccine or cure for HIV/AIDS (UNAIDS 2004, Ristola & Sutinen 2002). A recent HIV vaccination conducted by the US army in Thailand was only 31.2% successful (BBC News 2009. And now the 44% to 73% capacity of Truvada (the first FDA approved drug for HIV prevention) to prevent HIV remains unsurpassed (BBC News 2012). |
| Only a Severe Fever | | To be candid to you, I was in church one time our pastor was saying that 'what we now know as HIV was actually what Peter`s mother had as severe fever in the Bible' (tp0389fn) | |

| | | | |
|---|---|---|---|
| Unnecessary Struggles | | ...so luckily for me after some years, by the time I started taking my drugs and all that, I was that haa! Is it that simple? Then I was dying inside – for I feel free, I just live like a normal person, as if nothing has wrong with me (as0481fn) | Deadly and fearful picture of AIDS like: "*AIDS devours its victims before your very eyes AIDS*" (Clarke 2004, 222) still exist in the mind of many |

**Table 9.** Knowledge of participants on the origin of HIV/AIDS

| **Themes** | **Finnish Conceptions** | **Nigerian Conceptions** | **Results of earlier research** |
|---|---|---|---|
| A Virus that Existed in the Tropics/ From Time Immemorial | It must be a virus that has always existed i the tropic. Something like this existed allready in the anchient Egypt (ms9367ff). | HIV has been even before Christ. To be candid to you, I was in church one time our pastor was saying that 'what we now know as HIV was actually what Peter`s mother had as severe fever in the Bible'. So I will say it has being in the system from time immemorial. (tp0389fn) | The origin of HIV/AIDS is shrouded in mystery. The theory that it might have come from monkeys is questioned as some scientists argue that HIV in humans and SIV in monkeys are not compactable (Kirchhoff et al. 2008) |
| Maybe from Monkeys/ A Disease from God | I know that they have found in some monkeys disease very close to it, if not the same but they don`t know if – that is the way it came to you know humans, maybe is from monkey, but it was something – I know they have started researching it New York I think in the 80s where a lot of homosexuals died of this disease, that was fast accumulating (sn9975ff). | ...all I know is that everything is from God, because is written in the Holy Quran that "there will be a time that I will send emm, I will send a problem that you will never find a solution to it – to the world", and I know this is what, this is going on now. God has send a problem when we are searching for solution you can`t find. If it has not happened there won`t be God fearing, people will not fear God, so let me say everything is from God (as0481fn) | |
| A Foreign Illness from the Western World | | We do believe that, general believe is that HIV actually came from our expatriates. Okay? Those who were exported abroad, taken in form of slavery and all of that, and they were brought back. So the general believe is actually HIV is a foreign illness brought from abroad, from the western world (tp0389fn) | AIDS first emerged in America in the early 1980s when the American CDC published in their *Morbidity and Mortality Weekly Report (MMWR)* the unusual cluster of Pneumocystis Carinii Pneumonia (PCP) in five gay men from Los Angeles suffering from Pneumonia (MMWR 1981) |

| | | | |
|---|---|---|---|
| Unimportant | | There are so many history, one say is gay from America, one say a monkey in Africa but for me there is no need, am looking farer than that. If you find a fire burning what will you do? (ht0484fn) | |

**Table 10.** The negative conceptions of participants on HIV/AIDS

| **Themes** | **Finnish Conceptions** | **Nigerian Conceptions** | **Results of earlier research** |
|---|---|---|---|
| Stigma of Shame/ Negative Labelling | Unfortunately it has got a stigma of shame and it is socially restricting. Not so much anymore, attitudes are chancing... The social and spiritual stigma should be lifted (ms9367ff) | ...all that they believe is only through sexual intercourse – that is their own! And I told them I never flirt around, I was a virgin when my husband got married to me (as0481fn) | A HIV-positive woman (Gugu Dhlamini) was stoned to death in 1998 by men in her community in South Africa after she had declared her HIV-positive status on radio and television (UN 2007) |
| Something Black, Red, White and Round/ A Disease that Affects One Mentally | Something black and red, black like the stigma, death. Part of the red is the blood, is also very powerful. And maybe it would be like round thing with black, red, and white, because it has all that included, it has life, death, everything included in it (sn9975ff) | ...some time HIV if you let it affect you, it will affect you mentally, yeah you cannot do anything actually not only in education, cannot cannot even communicate (ht0484fn) | In Anderson & Spencer (2002, 1348) one participants in painting a picture of AIDS drew a wide vertical line beginning at the top with the first phase, diagnosis, coloured red meaning things are not good. The phase that followed was shaded blue and labelled 'medication, education, and acceptance' to reflect the sky that he could see from his inpatient bed. The finally stage was coloured bright yellow and labelled 'hope.' |
| Limited Lifespan | The doctor then proceeded telling me I had about 10 years to live (ms9367ff). When I got it in 1999, I was told I will live maybe 10 or 15 years (sn9975ff). In some country I think that the truth is like your life expectancy isn`t so rosy with the disease. But in Finland is kind like everything works just fine (sh0485ff) | | The participants of Anderson & Spencer (2002) envisioned AIDS as people who are reduced to skin and bones, extremely weak, in pain, losing their minds, and lying in bed waiting for the end. One woman among them perceived AIDS as a skeleton crying |
| Fast Spreading Disease | ...but ionly started to spread more videly when tavelling was made easier, cheaper and faster (ms9367ff) | | Sexual contacts which in many occasions accompany migration and tourism is facilitating the spread of the disease (Clarke 2004), and since people travel more nowadays, more need to be done in taming the spread |

| | | | |
|---|---|---|---|
| Linked to Gay Sex, IV-Drugs and Promiscuity | It is linked to gay sex and iv-drugs and promiscuiety (ms9367ff) | | In the 1980s, the predominant plot in Finland identified AIDS as gay disease (Clarke 2004) |
| A Stamp of Self Infliction | It has a "stamp" of being a self a self- inflicted sikcness. So in fact are many other diseases but they do not carry such a stigma. People suffering from cncer etc get a lot of symphaty and support even though most of the cancers can be self afflicted too. And cancer of cervix has also beeb proved to have started from papilloma-virus spread by sex (ms9367ff) | | The disease is often linked to immorality and promiscuous sex which makes it sound more unacceptable, and many for lack of knowledge or limitation of it go extra miles in stigmatising PLWHA. In Cao et al. (2006) study of 601 female migrants in Shanghai, 54.6% of the respondents believe that those who acquired HIV through sex and drug use deserve it |
| Stigmatisation Due to Few PLWHA in Finland | the biggest issue about this disease is stigma....Is a big issue in Finland there are not that many is not like everyone know someone who has it, or if they do, they probably don`t know they have it,... I think the stigma is – I don`t know if it will ever ever change or maybe slowly, you know people use to think about epilepsy is something terrible – it was very stigmatised ... I think it makes people not to go and test themselves, which is the worst thing to do, I think I think that stigma make people afraid of – they don't wanna know, they just don't wanna know (sn9975ff). I think they have to [change] because people in general can`t be that stupid their whole life, I think at some point they will see it as any other disease like any other. I don`t know how long is going to take, but is gonna take hard work. I don`t think that people will carry on being ignorant for 10s and 10s of years (sh0485ff) | | The overall HIV/AIDS statistics in Finland and Nigeria are 2600 and 3,300,000 respectively (UNAIDS 2011). And based on the UNAIDS/WHO (2008) global HIV/AIDS epidemiological fact sheet, HIV prevalence among young Finns and Nigerians (aged 15 – 24) are respectively 0.1% (male 0.1%, female <0.1%), and 1.6% (male 0.8%, female 2.3%). |

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| Constant Reminder of Death | ...obviously someone die at some point but when you get some reminder that you are going to die at some point, then it can like put new perspective... when I take my pills, I remember that there is something why I have to take them (sh0485ff). | | Anderson, Ryan, Brown, Gray (1999) attested that testing positive to HIV/AIDS is like receiving an emblem of death. In Anderson & Spencer (2002, 1347-8) a 29-year-old woman drew a picture of a grave with delicate red and yellow flowers and wrote on the tomb stone *"RIP Devoted Sister and Daughter."* Over the grave, she drew a black cloud with the sun peeking around the edge and described it as symbolising her family's sadness at her death |
| People suffering and Dying | ...is really wrong that am doing well with drugs, there is 100s of people out there suffering and dying and they don`t get the same opportunity (sh0485ff) | | Awa &Yamashita (2008) confirmed that there are physical, mental and socio-economic health implications of HIV/AIDS |
| Restricted Travelling | ...we should be allowed to travel to every country. Some countries still have restrictions (ms9367ff) | | In the 1980s, it was a requirement for many foreign students to take HIV tests before entering Finland (Clarke 2004). Recently US, China, and other countries have lifted travel ban on PLWHA, however many countries still refuse entry for PLWHA |
| Always the Criminal | All the Finnish participants extensively expressed their displeasures with the implementation of HIV laws in Finland, and advocate for a review on the law that permanently sees the HIV-positive people as criminals and the HIV-negative people as victims. Their stories can be found in the text. | | Some legal scholars argue that criminal laws on HIV are exceptional in the sense that it is enough to prove that the accused has engaged in forbidden act. This makes it appear as though safe sex is the sole responsibility of PLWHA (Clarke 2004). |

**Table 11.** Positive conceptions of participants on HIV/AIDS

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| Not a Death Sentence/ Healthier than those who are not Sick | No, for me I don`t think, but in the world there are so many people dying... somewhere else is basically a death sentence but to me is a bit like a chronic disease, in here everything is so good... I hope I will die of old age I can`t be 100% such of what is going to happen but am feeling positive about it.. (sh0485ff) | right now I know that people with HIV can live and live and live till they got old, nothing is in HIV ... is not a deadly disease... taking your drugs normally, eat food very well, you will live healthy more than those who do not have anything (as0481fn) | The study of Fryback & Reinert (1999) found out that cancer and HIV/AIDS patients who are positive about their disease reported better quality of life than before they were diagnosed with their diseases |
| Life Restorer/ Saving a Sister's Life | I have thought about the disease a lot in some way I think maybe you know is quite like a paradox, but and I found out that I have the disease and started thinking about it, and when I thought that I was dying in some strange way it gave back this life to me...(sn9975ff). In a way it have been keeping me healthy, but I don`t, am not healthier than before (sh0485ff) | Like me through me I saved one of my sister, and she is very active to work now ...in 2001.... There if they want to give her food, they pass it through the door.... with the experience I have... (full story in the text) (aw0071fn) | HIV/AIDS draws the attentions of PLWHA to their health. With the use of medications people living with HIV are kept well and productive for a long time (WHO 2010b) |
| One More Reason not to Start Using Drugs Again/ An Encouragement for Fidelity | But is also a sought of like like a life guide, one more life guide, one more reason not to start using. So in a way the disease sought of take cares of me, because it does take care of my health (sn9975ff) | ...it encourage people to be faithful to their partners (tp0389fn). Even at the age of it, some people still flirt around, but it has reduced it, it has reduced it unlike before. If you actually want, like now am positive, I cannot say I want to go and flirt, maybe if somebody else I don't know your status, I don't know whether you are positive, so whereby as a woman and a man you are positive and I am positive you sleep with me, and have sex with me, the police inside me (CD4 Cells), maybe your own virus may be different from my own, it becomes a problem for me for my drugs to work for me. (aw0071fn) | Addiction can be to a substance (alcohol, tobacco, drugs, etc) or non-substance (techno addictions, TV, social media, pornography, gambling, etc). At first people do them for pleasure, but later they do them because they are enslaved (Nedley 2011). |

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| HIV-Negative Children | Two of the Finnish participants have one HIV-negative child each | There is nothing wrong in marrying themselves. When they get married they will have a child that is negative, they will have a negative child (as0481fn) | People who have responded well to treatments have been able to pursue careers, raise families, and live healthy lives (Clarke 2004) |
| Normal Life | | Some people are living healthy, positively now and they are not on drug (aw0071fn). I thank God no sickness has made me not to eat, I will never come across a sickness that will never make me to eat (as0481fn) | Living with HIV/AIDS affects an individual`s chances of living a normal life (Koopman et al. 2000) |

# APPENDIX II

**Table 12.** Participants` experiences with getting tested

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| Worth Discovering Early/ Get Tested on Time | It is better to find it out earlier to prevent it from spreading further and to start treating it as early as possible (ms9367ff) Well, obviously then the damages, the major ones haven`t happened yet because it progresses over the years, so if I found out in 10 years, I might find out when I have AIDS so that will be catastrophical compared to the fact that I found out maybe like half months the time limit when I got it.... If you wait some years you don`t know what the virus want to do with your body so I think everyone should know as early as possible.... And I have many friends that still don`t haven`t gone tested even though they know what happened to me (sh0485ff) | ...is very very good to find out one`s status earlier, because if I have found out earlier, maybe I wouldn't have been on drugs by now, maybe I will be eating good food. I already I have known that I have the virus, I would not allow it to bring me down. So I will know how to keep myself, is because I did not go, I did not go to find out my status, that is why the virus was able to bring me down (aw0071fn) | It is important for individuals to discover their positive status early. That will enable the infected individuals to take necessary steps in prolonging their life and avoiding spreading the disease to others (WHO 2010b) |
| Frequent Screening | | I use to go to the hospital every six six months to test myself. I was tested negative before the last time I now tested positive..., then I was so scared because of the friends I was going out with, I thought I could have it and all that, but later on when they brought the result, luckily for me I was negative (as0481fn) | |
| An Opportunity to Start Fighting it Early | | ...knowing status early I will say is a good one, in the sense that it gives you the opportunity to start to fight it early.... But knowing early will give you the drive to try to fight it (tp0389fn) | In a study of 3,556 British men and women diagnosed with AIDS, 49% of them learned that they were infected with HIV just nine months or less before they were diagnosis with AIDS *(Porter, Wall, & Evans 1993)* |

**Table 13.** The meanings of testing positive to HIV

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| Bad News made Worse/ You Came with Somebody? | I was 8 months pregnant by then. All this time, the doctor did not even offer me a chair where to sit while listening the bad news (ms9367ff) | ...even from the mode "you came with somebody", I knew my result was positive (ht0484fn) | |
| Additional Sorrow/ Crying, Crying, Crying | ...is like my life wasn't happy before it, now it was like even more unhappy (sn9975ff) | And then I was pregnant, and when I am alone if you see me I will be crying, crying, crying. Crying I will think of the baby, think of me whether am going to be alive because the awareness wasn't like this then. Then when I got in contact with doctors from borders (i.e. doctors without borders), those white people, they gave me hope, when my hope was lost (aw0071fn). When I got to school I couldn't tell anyone. I cried for the whole day, and I moved on with my life (as0481fn) | A person who feels secure enough to cry and release inner emotions can be quickest to recover because shedding tears gives a person the opportunity to begin to heal and recover from a loss, disappointment, grief, etc (Orr 2003). |
| This is it/ The End: | basically when I found out I thought that this is it, am dying good bye, but over the years I just realised that is not like that life goes on you know ... I think I thought that am dying and soon, I have no idea what was happening because I didn`t have so much information about the drugs and everything, I was thinking that okay this is it, I have few years or something, so yeah it was really devastating but after when I had time to think about it and people like nurses explain everything about it and so yeah, the first reaction was death or something similar (sh0485ff) | I thought that was the end, I thought that was the end (as0481fn). As a human being, is normal to think, the image that comes is death, that first impression was created (aw0071fn) | According to Clarke (2004, 232) "*the first reaction to testing positive was the fear of death and the fear of stigmatization*" |

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| Being Hurt/ Being Ill Treated | I think I have been hurt by the disease, and not by knowing it, I think the best alternative will be not to have it. The next best is having it and knowing that you have it, and the worst will be to have it and not know it. Is like if I will get cancer, I will like to know that I have cancer, even if I will know that am gonna die of it, I would like to know. (So that you start taking care of yourself?) yes, yes (sn9975ff). Knowledge increases the responsability and pain, but I'd rather know it than to infect enyone else (ms9367ff) | His own response to the whole thing was what made me panic a bit. Well, along the line it was obvious that he knew he had it but couldn't face me to tell me, I felt ill treated, because to me I believe he knew his status and didn't tell me. So he would have allowed me make the choice – if I want to live with him that way or not. So I felt a kind of ill treated and a bit cheated to (tp0389fn) | Knowledge is power (Vickers 1992) |
| No Big Deal/ Unscarred | It really didn`t, it wasn`t that a big deal you know when I heard it, it wasn`t like good news, well I thought I will die of the drugs before I die of the disease (sn9975ff) | It couldn't move me, and I said really? Okay. I was not scared at all ...so I just graced up.... Hearing the news I wasn't scared because I have little knowledge about what HIV/AIDS is all about, and I knew it wasn't a death sentence, I knew from the awareness, from the little knowledge that I have gathered I knew it wasn't a death sentence. If you test positive to HIV disease, the next thing that come to your mind is for some, for some it could be really a death sentence actually (tp0389fn) | |
| Undisclosable Big Dark Cloud | And then it was this, it was a long time, maybe 6 months it was just this big, big dark cloud inside my head, I didn't want to talk about it, I didn't want to tell anyone, I just walked around. My life was just a mess, I had no hope at all (sn9975ff). Like when I found out that period really rocky and stuff, but after that I think life went back to normal basically (sh0485ff). | | |

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| Self-pity and Drinking | When I found out, that was a short period of self pity and drinking, but after that I haven`t really thought about it because at least in my mind you know sickness have happened what`s the point of like going over them because what happened happened, it could have happened to me or someone else (sh0485ff) | | Self-pity is a frequent response to stressful incident, and with respect to personality, Stober (2003) shows that it has strong associations with neuroticism – particularly depression. |
| Limited Social Life | My social life was limited quite a lot in the beginning . Mainly because of the initial shock I had (ms9367ff) | | The quality of life of the PLWHA HIV/AIDS in often affected by the disease (Skevington, Norweg & Standage 2010) |
| Recovering from Lousiness | I think that before I knew I got it, I think I was lousy at (name of the place withheld), try to study a bit and didn`t know what to do with my life and emm you know, and then when I found out is like. In the beginning I really thought that am going to die soon, younger, or something, like it really pushed me to achieve my goals like to study and start thinking what I will want to do. Obviously someone die at some point but when you get some reminder that you are going to die at some point, then it can like put new perspective, I wanted to do like something with my life, I wanted to do sooner than wonder around (sh0485ff) | | A wake-up call |

**Table 14.** The experiences of participants with accepting HIV-positive status

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of Earlier Research |
|---|---|---|---|
| Confirmation Testing/ No Choice | ...there was another test done, after the first "quick" one. It was a long time ago, I don´t remember any details (sn9975ff)<br>The doctor gave me an open note telling me to take it to the lab. I had to be tested for second time (ms9367ff) | ...when you go for that test and they say you have the virus some will say God forbid. It was very easy for me; I accepted it because there is nothing I can do about it.... It was when I went for confirmation; I thought they will give me another report. But that day I waited after the result came the same, I accepted my fate.... Yes, there is something like that because some of the machine they are using outside, some of them doesn't give you the correct result. That is why if you do it outside lab, they will send it for this thing for confirmation (aw0071fn) | After a HIV/AIDS positive result, a confirmation test is often done to affirm the result |
| Hard to Accept | …mentally it was hard to accept (ms9367ff) | ...for me it was really hard... some people might get infected and still hide themselves haa it can`t be me, how did I get it? Why should you be questioning? (ht0484fn) | In Anderson & Spencer (2002, 1347-8) one participant who is struggling to accept the disease says, *"I hate that word. I'm still trying to accept it, I think. Yes, I am trying to accept it"*. |
| Identity Crisis | ...is not part of my identity although is in me, is not who I am.... probably it has affected my my self image different times in different ways (sn9975ff) | | The disease is often linked to immorality and promiscuous sex which makes it sound unacceptable (Clarke 2004). |
| Permanent Stamp | I guess is a part of me, nowadays is something I will have to live with the rest of my life (sn9975ff). We are to change what we can and to accept what we cannot change and to ask wisdom to know the difference between these two (ms9367ff). | | A participant in Anderson & Spencer (2002, 1347-8) says: *It's finally sinking in that I do have it and I'm starting to feel lousy about it* |

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| Not Running to Churches | | Well it`s one thing to know your status early, and another thing to accept it. When I got to know my status I didn't fight it like it`s not my portion. I didn't run to churches, I didn't run to you know like our mentality here – trying to seek help where there is none, I accepted it in good spirit and moved on. That as a matter of fact brought me to where I am today. So is one thing to know your status and another thing to accept it... accepting it is another thing, another big challenge (tp0389fn) | |
| Living Fine | | Normally you will think about that, 'how I wish I don't have it', but will you blame God for everything? When I had it I felt so bad, but right now am happy, and am living fine (as0481fn) | |

**Table 15.** HIV associated emotional stresses as experienced by participants

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| Feelings of Hiding from People | I think is the barrier I create myself you know inside, you know I have this feeling that I have to hide from people (sn9975ff). I feel unattractive and old, even though people thell me otherwise (ms9367ff) | | In NordPol (2007), the respondents sense that sometimes people are afraid of them and keep physical distance. |
| Short Time of Being Weary | I can`t say that I`ve had depression as the disease depression you know but just this short time of being weary. I have never really been depressed about it (sn9975ff). Am not angry, bitter, it just am living with it, I don`t get depressed or thinking about it (sh0485ff) | | One informant in Anderson & Spencer (2002, 1345) who chose to stress less says *"I try not to let it bother me because my viral load and everything is real low...."* |
| Loneliness and Sadness | I often feel lonely and sad, lately not as much as before. My daughter is soon flying away from the nest as she is becoming of age. I wonder how it is going to be, when my daughter moves out. I see my future rather lonely (ms9367ff) | | For the immigrants in Finland who are living with HIV/AIDS, their biggest challenge is coping with loneliness (Clarke 2002) |

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| Drinking Heavily | Yeah! I was really like depressed, and I think that I was really like drinking heavily.... I think it was something like 6 months I was really like out of it, but then I just process it (sh0485ff) | | Learning that one is HIV-positive may open doors for drugs use, destabilisation of relationships, income and shelter loss, etc (Stevens & Doerr 1993) |
| Suicide Thoughts and Attempts | I tried it several times. Did not succeed. It was mostly because of the depression (ms9367ff). I think maybe at some point, it was the time I was living in [name of the place withheld], I had just moved there and found out that I had no family, I had no friends, it was like I was there all alone so it was really hard (loneliness) (sh0485ff). Well when I was using [drugs], not after I quitted (sn9975ff) | | Clarke (2004), Préau et al. (2008), and Stevens & Doerr (1993) revealed that the first reactions to testing positive to HIV are shock, fear, anguish, and suicidal thoughts. One participant in Anderson & Spenser (2002, 1348) who wanted to take his own life said: "When I first found out, I wanted to kill myself and just get it over with. But now it's different. I want to live and just live out the rest of my life". |
| Guilt | Sometimes. I did this myself by not protecting myself. By allowing myself to get into a situation like that even though I knew better. But not so much anymore (ms9367ff).I knew what to do to protect myself but I kind of didn`t do it, it`s kind of own fault (sh0485ff) | | For PLWHA the feelings of guilt and anxiety may occur frequently (Clarke 2004) |
| Prison of Shame | It is hard to be a social recluse. Even harder to understand that the imaginary walls are the thickest and that even if they were to be broken, the prison of shame is inside you (ms9367ff) | | The primary duty of HIV/AIDS organisations is to provide psychosocial support to PLWHA (Clarke 2004) |
| Sometimes a Big Issue | So I can`t say is not a big issue in my life. There are days is not an issue, but there are days and night is a big issue, it goes up and down (sn9975ff) | | |

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| Painful Separation | | My first husband sent me packing while my baby was 2 weeks old, so I catered for the child and move on with my life (as0481fn). I think women who are positive you know some their husband ran away, some their husband is late you know, so they are left with the burden of taking care of the children (tp0389fn) | Learning that one is HIV-positive may open doors for drugs use, destabilisation of relationships, income and shelter loss, etc (Stevens & Doerr 1993). |
| Hardship due to Less Productivity | | Is when things are tough, when am getting sick, and when financially everything is [tough] I will start thinking, which is because one can no longer do the active and productive like before (aw0071fn) | In Anderson & Spencer (2002, 1345) one participant said: *"It just took my whole life and turned it upside down. I can't do a lot of the things I used to. I lost a house because of it. Everything I worked for I lost."* |

**Table 16.** Coping strategies suggested by participants

| **Themes** | **Finnish Conceptions** | **Nigerian Conceptions** | **Results of earlier research** |
|---|---|---|---|
| Not Part of Everyday Life/ Just Someone with Normal Illness | ...the disease is not part of my everyday life, I don`t really think about it ... but in general I think it has it has like inside my head (sh0485ff) | I don't identify myself as someone who has AIDS, I identify myself as just like someone with normal illness, I don't have it in my mind [always]. I think about it when am down (aw0071fn). I never even believe that I have HIV, I live like a normal human being, nothing is wrong. I know I have it but I never look like someone who have it, so it never have any effect on me (as0481fn) | |
| Less Thinking/ Not Thinking | I don`t think about it often because it`s really difficult to be scared about something you don`t know (sh0485ff) | I don't think about it, I don't even think. They should try to be happy always. They shouldn't think about anything, they shouldn't let anything border them. If they have anything in mind that is bordering them let them share it so that there will be a solution (as0481fn) Initially when I feel sad I think about it, and then I just pray this thing may not kill me, this thing may not kill me, but now I don't, for once I don't even think about it. I don't let it border me.... The first thing is to remove their mind from the virus (ht0484fn) | Thinking about the disease can be very problematic because it makes one to feel that the disease is much an obstacle than it really is (Anderson & Spencer 2002). |

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| Love to Live | I think that I had some ideas like what to do now, like is worth living and stuffs, but then basically at some point, I just decided that okay, do I really want to die or do I want to start on living, I just decided that okay now it is time to get up from the bed you know push it so (sh0485ff) | ...just for me I have taken the decision am going to live, am not going to die (tp0389fn) immediately is 8 o`clock the alarm will remind you. Although is not easy, is not a very easy thing but the decision again depend on me, i.e. I have that decision to live.... Some they will still ask them, some fail to adhere to the instruction, for me I really want to live, I really want to take care of the children God has blessed me with, I really want to live for that man who has been standing by me (aw0071fn) | Finland has one of the highest suicide rate in the world (Yle July 2012) |
| Self Esteem | ...you know life, I didn`t have any goal in life you know the future didn`t seem like anything great to look forward to it, but now and so the disease is just one thing you know, but when I got clean and started living a normal life and step by step I have built myself consciousness, I have started to consider myself as a normal human being (sn9975ff) | They should empower themselves in many things; they can do business, they can go to school... so they should empower themselves. They shouldn't look down on their selves, they should look their selves as a normal person. When they look their selve am okay, they will move on with their life. But when they look their selve ah very soon I will die oh, they will fold their hand, they will not be able to do anything, they will be powerless (as0481fn) | HIV/AIDS related stigma and discrimination should to be fought because it leads to identity crises, isolation, loneliness, low self-esteem and lack of interest in fighting back against the disease (Valdiserri 2002) |
| Fight Back/ Self Support | We must fight so that the ones who come after us would have it easier! ...I was told by a younger positive woman how she always admired me and thai I was kind of an example for her. She too started to study.... All in all, I feel like I should never ever give up (ms9367ff). I want to try to live so that it doesn't keep me from doing things, I want to like achieve things, maybe that, I want to work against my feelings that say hey don't do this... I have had this disease for a long time, I have had all these years to you know think about it and come to peace with it (sn9975ff) | First of all, they should not have sex without condom, they should try to protect their selves always except they want to have baby. Secondly, they should eat fruits a lot. Thirdly, they should rest, they should find time to rest, and they should make sure they are happy always, they don't feel sad. Someone who is living with HIV can exercise – nothing is wrong with that. Make sure they drink a lot of water (as0481fnYou take good food, take good care of yourself, if you have any illness treat it. I have good image about myself, I don't allow the disease to put me down. All that I knew was that I kept to the instructions of the doctor, and my husband was by my side, unlike other people, he was by my side (aw0071fn). ). I noticed the doctor that counselled me, even the counsellor herself made mention of how intake of minerals and vitamin can help (tp0389fn). | Holzemer, Henry & Reilly (1998) study of 249 AIDS patients associated higher level of pain to lower quality of life. |

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| Someone to Talk to/ Visiting One Another | Someone to talk to... when I feel lonely or feel sad, it make me feel even more lonely or sad... but I have people I can call, people I can yes HIV-positive friends, and also other friends, calling them helps me to recover from lonely feelings (sn9975ff) | Is actually like when we pay a visit to their home, when they see the rest of us, they know that is not just one person (tp0389fn) | Anxiety and ...depression are the most common psychological problems for PLWHA (Virk 2011). In Issiaka et al. (2001) study of the experiences of HIV-positive women in Burkina Faso, one out of every two women wished to meet another infected person in local NGOs to share viewpoints |

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| Support Group Meetings | Positive people meeting each other and supporting you know like – hey we can do it you know a group is always stronger than one person, I know that I have gotten a lot of support from people that had it longer than me, And also it has helped me, and I know I have helped other people who have now just found out about their disease. I can tell them hey I have lived with it for 12 years you know; it hasn't really affected my life that much... it is very supportive, and they are helping me to cope with it. Just you know support, knowledge and information, and phone numbers and contacts... if I have something I really need support about it, yeah I got sometime this positive ladies – positive women group (sn9975ff). In Finland, I think that it will be really important for HIV people, like positive people to see each other more ... in Finland the circles are so small, so l think it`s real difficult for people to reach out and get to know other people with HIV, so then they could see that they are not alone .... I have so many friends I always talk with them, ...but I know there are so many people who are lonely and don`t have so many friends, so it will be really good for them to have a kind of like long time relationship with someone to talk to, is really important ... we go out, we go sometimes to movies, you know something have fun together (sh0485ff) | Support group is a place where you can come and share experience with PLWH, we come there to share our mind. If you have problem, if you cannot tell another person at least you have your brothers and sisters, [and say] this is what is bordering me oh, if any of us has solution to the problem, we will tell that person (aw0071fn).The support group we meet share our different experiences and challenges; whatever it is one has suffered. Some it could be financial problems and especially when the love and support is not there (tp0389fn). | Peer-support meeting is becoming increasingly important (Harris & Larsen 2007). For it promotes adherence to HIV/AIDS medications (Marino, Simoni, and Silverstein 2007 |

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| Being Strong | | I never felt bad, I never felt bad because I know I will come across it. It never affect me because you don't need to talk to anybody except God (as0481fn) | Farber, Schwartz, Schapner, Moonen, and McDaniel (2000) acknowledged that lower psychological trauma, better quality of life, self-esteem, etc enhances coping with HIV/AIDS |
| No to Sorrow and Self-pity | | Is not good to feel sad, if you feel sad you are killing yourself. If you have anything in mind you are killing yourself – that is what HIV did not want! I know what HIV want and I know what it does not want, so if I do it I will be killing myself (as0481fn). One doctor told me that depression is one thing that kills faster. Not just with someone living with HIV, but depression in any illness kill faster than the illness itself. So my dad pleaded with me not for any reason get depressed (tp0389fn). As a person, when I start feeling sad, I will start bringing problem to myself. It doesn't make me sad, am always happy (aw0071fn) | |
| Helping Others | | I give out a little support almost on every aspect of my life (ht0484fn). | |
| Public Support | | By employing them you are giving them right to life, because when they, no matter how small the salary is, when they have a job, at least when they are eager I want to dress up and come to work, I want to make an impact in my workplace, their mind is removed from the disease (ht0484fn). The support group I always go has helped me a lot – financially, they give us soft loan to upgrade ourselves, then we pay back (aw0071fn) | Social inclusion and perceived improvements of access to health and social care improves quality of life for PLWHA (Skevington, Norweg, Standage 2010) |

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| True Empowerment | | ...empowerment like those that want to learn hand work, and if they learn the work you establish they. You establish them, you monitor them to see if the business is going. Because there is some of them they will learn the work you won`t establish them, and you say you have empowered somebody. Is just like you send somebody to learn trade and you don't ... they are doing it, in Nigeria they will say they want to empower positive people, they will say they will train you a day or two, the only thing they will give you is your meal for that day. In Nigeria, they are not doing it well enough (aw0071fn) | |
| Standby HIV-positive Counsellors | | So is better for a positive person, is he that wears the shoe that know where it pinches. Like in the hospital, that is what we are trying to see if they can do in the hospitals or health centres. Make sure they take positive male or female so that anybody that test positive some will say when they test positive let the grass open let me go in. Immediately they come to you counsel them – when you see that person, you see that the person then disclose, immediately you disclose to that person, the person will calm down, he will know that is not the end of the world (aw0071fn) | |

# APPENDIX III

**Table 17.** Impacts of HIV on physical health conditions

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| HIV-negative Babies | I know that in Finland I think that there have been 100 or something positive women that have given birth and all the babies have been health, so I know that that is not the problem (sh0485ff) | so right now am married to someone who is not HIV infected, and also I have two children who are not HIV infected (ht0484fn) | |
| Healthier than Before | | Even if I have HIV, does it show in me? So far as it does not show in me, so am fine. Am even more healthy than before (as0481fn) | About one-third of the 450 HIV/AIDS patients studied by Szaflarski et al. (2006) felt that their life after diagnosis is better than it was before being diagnosed with the disease |
| Looking Good without a Make-up | | ...then I was very sick I could not even fight back anything that get on my way, but as you can see, am sure even without the make-up or things like that am looking good. Nothing, nothing bad about my health (ht0484fn) | |
| Just Being Chronically Ill | If I fall ill, I will need help, but I don't think I'll be more dependent on health care than other cronically ill. I can travel to 3.rd world countrries as long as I'll have my supply of medicine with me (ms9367ff). obviously it has affected my health because I have HIV but at least at this point because I have had it for 7 years now, I don`t am not any more sick than I was before .... (sh0485ff) | | In Anderson & Spencer (2002, 1345) one participant who does not want to over trouble himself with the disease said "I try not to let it bother me because my viral load and everything is real low...." |

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| Low CD4 Count | ...my viral load even when I was diagnosed was really low, that`s good thing, even when I was diagnosed my CD4 count was then like – I ...don`t remember, was really low, like the starting point... so my CD4 count went somewhere around 300 ( instead of 750 to 1500), so then we decided that I should start, otherwise my viral load is still really low, but the CD4 count is what they are like looking (sh0485ff) | ...when I went there I never started taking drugs, but when it get to a stage, they will check your CD4 count, if it is low you will start taking ...drugs, is the doctor that will recommend a drug for you (as0481fn) ...they carried a test on me, and I was still doing very well, my CD4 count back then was still about 80 [800] something, I didn't need to start ARV immediately (tp0389fn) . I was really down then, I cannot even walk then. My CD4 was very low! very low almost at the point of death (aw0071fn) | |
| Bartered Body Image/ Disfigured Body | All the fat has disappeared from the face and limbs and accumulated int the waist area. It looks like I am pregnant. My tummy is upset at times (flatulence and diarrhea), I have night-mares, rashes and have had several allergic reactions for the drugs they have used on me (ms9367ff). | ...the effect was it make your chick go inside, your knee will go inside, even your bombom (buttock) will go inside that was how it was. And my stomach was big as a pregnant woman (aw0071fn) | |
| Early Menopause | I am 45 and my menopause has showed some signs of starting remarkably early... because the drugs eat away my testosterone (ms9367ff) | | |
| Becoming a Bit Slow | I have trouble remembering, I am a bit slower and it takes an extra efford to stay fo-cused and to picture complex entiretys (ms9367ff) | | |
| Frequent Illness | | Before I tested positive, I rarely fall ill, but the malaria thing kept com-ing you know in all I do. I take immune booster, minerals; I don't stress myself I rest.... Am AA (genotype) with the way I am, being AA am very prone to malaria HIV-positive or not. I have met people who treat malaria every two to three weeks, and they are negative, so I don't fall sick often because I am positive (tp0389fn) | PLWHA are at increased risk of clinical malaria, severe illness, hospitalization, and death (NMFS 2011). |

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| Prolonged Fever | | I was reducing in weight. Malaria, headache, then I had a very long hair, I had to scrape off the hair.... Normal persons, their malaria can take a day or two to go, but our own since own immunity is not that okay, it can take about a week before we are okay, then the whole system will come back to be better again, so is not very easy (aw0071fn) | Many of the PLWHA in Nigeria and their families are often frustrated with the challenges of managing the disease (Ogun-juyigbe, Adeyemi & Obiyan 2009) |

**Table 18.** Participants` conceptions on HIV medical treatments

| **Themes** | **Finnish Conceptions** | **Nigerian Conceptions** | **Results of earlier research** |
|---|---|---|---|
| Regular Check-up | Now is just every three months I go to the doctor (sh0485ff). Because I have to go see doctor every 4, 5 or 6 months, am under this intense scouting, you know it`s, that positive side is if I will get any other disease, it will be detected very early, at the very early stage (sn9975ff) | Is an advantage, is an advantage, even if I have any disease the doctor will know. Time to time, there is a limit to anything, when it get to some time you are taking your drug, maybe some months, they will ask you to go for some test, if you have any disease, the test will carry it out (reveal it). Because the drugs too always, it might have side effect. That is how the doctors always care for, they will place you on test always, if there is any problem they will tell you (AS0481N). I think is an advantage, visiting the hospital frequent is good for other things to be detected. Like I could visit doctor monthly and he run some tests. Some three months, some six monthly – twice a year. For me is an advantage because ordinarily, this is Nigeria let's be realistic, some people will not even see a doctor for years they will say nothing is wrong with them. So for me that is also an advantage (HT0484N). They have done series of test to see if there is any other infection that you have, then they will treat that apart. There is this savica (cervical) cancer screening they were doing for the women; at list it was an opportunity. I went for the test, they have to test my womb to see if there is anything like cancerous something there. It gives you, it is a way to see if there is any other disease in your body, they will detect it and they will treat it (aw0071fn) | The availability of HIV/AIDS treatments has increased the chances of financial independence of PLWHA. The treatments has helped improved their work performance and decreased absenteeism from work (Beard, Feeley, Rosen 2009) |

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| Daily Swallowing of Pills/ Adherence to Doctors` Prescriptions | I have to take my medication everyday same time, so is up to me (sh0485ff) | ...when you are on the drug taking it regularly, the way the doctor – adhere to your treatment, you will live longer. At the initial time I was worried, but my husband, even the children they always, at time the alarm will be ringing and I will forget, is the children that will mummy mummy is time for your drug. That is why they always tell us in the hospital, choose a treatment partner, tell somebody that will always be reminding you about your drug. The thing is now part of me (aw0071fn).<br><br>It has got to a stage I just have to. If I don't take my drugs I won`t feel free. Maybe I mistakenly did not take it, I will not get myself through that day, so is part of me, I never even want to try and careless, that is why I always have alarm to remind me of it morning and night. Once my alarm ring I stood up and take it immediately (as0481fn).<br><br>From what my counsellor told me "just feel like you have to eat, no one can go a day without food". So the same thing apply to the drug, I can`t do a day without it. Well am on two combinations, I take one twice a day, and the other one once a day (tp0389fn). | The progression of HIV in the body can be slowed to a near halted with HIV treatments (WHO 2010b) |
| Boosting Immunity | Because my immune system (CD4 count) was low, but with the medication it is normal again, it was between 100 and 200 I think, it`s now I think 700 (that is about normal) (sn9975ff) | | The most significant impacts of the treatment are that more PLWHA are alive and coping with the disease (Clarke 2004). Echeverria, Jonnalagadda, Hopkins, & Rosenbloom (1999) associated PI (protease inhibitor) treatments with weight gain, deceased viral load, increased CD4 counts, fewer opportunistic diseases, and better quality of life |

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| Wired Side-effects/ Change of Medication | The modern combination drugs are making me tired and affect my body. They have all kind of weird side- effects (ms9367ff). All the fat has disappeared from the face and limbs and accumulated int the waist area. It looks like I am pregnant. My tummy is upset at times (flatulence and diarrhea), I have nightmares, rashes and have had several allergic reactions for the drugs they have used on me. Some of them so severe, I had to be rushed into hospital because I could not breathe (ms9367ff).<br><br>...maybe at some point I might have to change my drugs ... it`s very tricky, you just have to be one step ahead of it (sh0485ff) | The first one there was, the first one I took, the first combination I took, the effect was it make your chick go inside, your knee will go inside, even your bombom (buttock) will go inside that was how it was. And my stomach was big as a pregnant woman, so when I complain it was there they told me it was the effect of the drug. So they had to, the only thing they had to do, change the, remove that emm emm (tried in vain to remember the name of the drug that was replaced), and put another one. Some might have rashes all over, and some people it doesn't affect them. This one am taking now, another thing am noticing is that it use to reduce your (my) blood level. Last month, the time I was sick, I noticed it my blood dropped, so I had to buy multivitamin (supplements) and vegetable to build it up (aw0071fn).<br><br>If they give you the first stage, if it don't have, if it has side effect, they will ask you to come back to the hospital, they will give you another one. I never have any side effect since I have been taking it (as0481fn). When theirs are giving one problem by the time they are placed on another drug is too late and things like that, but for me once they placed me on drug, within a year, within 6 months my viral load has reduced to what we call undetectable. And I have been, I don't have any drug reaction, thing of such I have never seen. I don't have any drug reaction or whatsoever, I will say thank God (ht0484fn). | Antiretroviral drugs have numerous side-effects (Nord-Pol 2007), which could lead to profound weight loss, reduced quality of life, and missing doses (Douaihy & Singh 2001). The drugs may also cause illness, fatigue, depression, and chronic disability (Clarke 2004). And due to ARV`s side-effects, Zimmet (2005) advises that caution should be taken before the prescription is made. |
| Lesser Side-effects | I think the treatment, you know I think the treatment now is really good, you know you can now live good healthy life, and side effects of the medications are getting less and less all the time (sn9975ff) | | |

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| Vaccination Seems Uncertain | I don't know a lot about it, but I know is very hard to find it. And I know that there has been some vaccination, there have been some research somewhere in Africa, and it has minimised the possibility of getting the disease 40% or something. I really think like safe sex and clean needles, needles protection proper, they are the best vaccination, 40% is not, I don't think before companies come with this 100% vaccination, maybe we should put more money on information and you know helping to stop it in other ways you know.(sn9975ff). The head doctor at Helsinki's infectuous diseases unit was not too optimistic about it, quess he did not want to give us false hope. The stem-shell treatment might be a solution! One day soon the serum will be found and a vaccine developed. Maybe those children born to us positive have got something in their system that could help (ms9367ff). | | Though efforts have been made on finding a vaccine for HIV, and the success has been slow. But a land mark was made by a HIV vaccination trial conducted by the US army in Thailand which indicated up to 31.2% success (BBC News 2009). And now the 44% to 73% capacity of Truvada (the first FDA approved drug for HIV prevention) to prevent HIV remains unsurpassed (BBC News 2012). But a Finnish company is planning to come up with something much better |

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| Limited Medication and Treatments | | Like now at times in the hospital, they only give us the ARV, other drug we buy that is what is, unlike before, if we have malaria they give us the drugs free, but now is only ARV... now if you have malaria you go to the hospital, they will just prescribe for you, they will say is out of, everything go and buy.... The test, x-ray and everything, if it was like before, they will run the test for free.... At times you will see them rationing the ARV – the drug they give us. If you are to collect your one month drug they will share it so that another person will get. Since last year we are losing a lot of people, people are dying – those that are tested, those who cannot afford to take care of themselves, it can be a little cold , like our malaria is different from a normal human-being.... some of the donors, those that are supporting us have started withdrawing. Those foreign donors that are helping us with our drugs and treatments; that is why we are finding it difficult in the hospital now, and government is not doing enough, now anything go and buy (aw0071fn) | |
| Rumours of a Cure | | As we are hearing, as we are hearing these days, we heard that the cure has come out some places outside Nigeria, all these European counties, the cure has come, but it has not entered Nigeria. You know if you go to some places you will be hearing all these sort of thing. You know why they don't want it to come to Nigeria is because they (private hospitals) are making a lot of money through this drug they are selling (aw0071fn). As a matter of fact I heard there is a cure in Europe that is what I heard. It has not come down to everybody now, but I heard there is a cure (tp0389fn) | Though the progression of HIV in the body can be slowed to a near halted with HIV treatments (WHO 2010b), there is still no cure for the disease. And as many anticipate, a cure would be found in their lifetime. One participant in Anderson & Spencer (2002, 1345) expressed his hope for a cure this way: *"I'm just happy to be here now and hope to be here when they find something."* |

# APPENDIX IV

**Table 19.** Opportunities forgone due to HIV-positive status

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| No Career in Public Service/ Change to a career on Social Work | I will never, I wouldn't want to pursue job or position where I would be public person, because I wouldn't want, I wouldn't want where all this thing all this to come out you know, I don't know if I would pursue it if I didn't have this disease, but now am sure I wouldn't do it, so in that way – yes (sn9975ff) | I did MD in mechanical engineering, so when HIV came into my situation in the sense that is not as if engineering is not a fine course, but I felt like going to talk to people, going to socialise, am going to go into social work, that is why am doing social work now. For me is an opportunity to do so many things, so for me sociology is a fine course (ht0484fn) | Opportunities for a bright future may be lost or destroyed by HIV/AIDS infection (Gachuhi 1999) |
| No Thanks to Cheaper School Health Care Services/ No Career with Private Schools | ...well that is why I don't go to, you know student health care, I don't even want to tell them there. Otherwise I know is something they can`t, - is cheaper I know they have to keep silent about it, but I still don`t wanna go there (sn9975ff). | At times when it border me is now if am teaching with a private this thing (school) tomorrow you say you are going to the hospital for your clinic, next tomorrow you say you will be going to another (aw0071fn) | |
| Unfulfilled Dream of a Second Child/ Loss of Opportunity for a Third Child | I have deamed about having another child before it is totally too late for me (ms9367ff) | It haut me, I wanted to have another child, when that my daughter was 6 year old, she is 12 now. My husband said no because of your health, I don't want a situation where you will have another child and be down... not even the negative children but my health, my health that matters (aw0071fn). Even before I knew my status, I will say I want to have three children, I have two now and one will come later (ht0484fn) | |

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| Constant Use of Condoms/ Frequent Use of Condoms | ...obviously we don`t want to have sex without condom because I don`t want to infect him (sh0485ff) | ...we use condoms. We don't use condoms all the time, we also have intercourse without condoms, he knows my viral load is low – undetectable, still we use condoms, but we are taking that risk, he also sees the doctor because you can`t do it alone. When you have HIV you can`t have your baby alone you have to like seek medical advice from the professionals (ht0484fn). At times I feel, at times I pity the man. He might not want to use the condom, like Nigerian, African mentality. At times I feel for him, at times I feel that condom he might not be satisfy, but there is nothing he can do, just to protect himself (aw0071fn) | |
| No to Breastfeeding | ...no breastfeeding, I did not, as I was told that there are risks (sn9975ff) | I did not breast fed, she was already on baby formula, hustling here and there (aw0071fn). I won`t say my first husband left me because of that because the doctor call him not to make love with me freely, but he does that. He said he cannot use condom with his wife. I will say maybe is because family issues, because I couldn't breast feed. But I know more challenges are still coming, am talking about the second husband I have married, I know am still going to face a lot of challenge. You know by the time I have child now, know I will never want to breast feed, then I will have challenges, the family will challenge me. Am going to face challenges for that, and I know no matter what, God will see me through, I know God will help me out (as0481fn) | In Anderson & Spencer (2002) one informant expressed her efforts not to infect her family this way: *"Just being conscious of it because when you got kids and when you got family that you live with, you have to be extremely cautious. You got to realize it at all times. It has to just be stuck in your mind that you have it and don't want to share it. Even attending to one of your children's cuts"* |
| Not Getting Pregnant in the Normal Way | ...because my boyfriend isn`t HIV positive so is much easier because well if I, obviously I just can`t get pregnant in the normal way, it doesn`t work like that I know it, but I have to start planning, tell my doctor (sh0485ff) | | |

**Table 20.** Participants` experiences with the disclosure of positive status

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| Open-ended Disclosure | Am afraid of rejection... I have some relatives that don't know about it, and I don't just find any reason why I should tell them, but there are lot people who know about it, my family, closest friends, and then people in NA (Narcotics Anonymous), but still is something I want to keep to myself (sn9975ff) | The sister that has been on my side, immediately I got tested positive I told her, but my senior sister it was last year I just told her, but the one that has been, my sister can keep [secret]. So you study people before you disclose (aw0071fn). When I had it I told them, my mum cried, my elder sister cried. My brother called me and told me not to cry, only God knows why it happened, I should feel free.... Only some of my fellow Muslim know, they even give me their baby, carry my baby, we stay together, share food together (as0481fn). | The negative perceptions of people about HIV/AIDS often add to the burdens already on PLWHA. And the anticipated negative or positive reaction influences the disease`s disclosure (Kimberly, Serovich, & Greene 1995) |
| Repeated Disclosure/ Disclosing to Spouse | ...at health clinic or something if am treated for something completely some other thing that is not related to this thing anyway and for some reason I feel like I have to tell about this as well I find that quite shameful(sn9975ff) | ...some people that are detected positive will say haa I won`t tell my husband, he will kill me. Already you have known the kind of man you have. In my own case it was not like that. He is a principled man, so he is a God fearing man, so immediately he saw it, he said there is nothing too difficult for God (aw0071fn). The man I got married to I let him know everything, every damp thing about my life, because I don't know how to lie. I told him this is what is going on, I have an issue already, am living with this, so how will you feel? He said okay, fine (as0481fn) | The disclosure of a disease such as HIV/AIDS may be more stress inducing than relieving it (Serovich, Kimberly & Greene 1998). HIV/AIDS being a disease that is not generally accepted in the Finnish society, the people living with it hide their status from friends and family members, but on rare occasions it is revealed to their partners who act as source of strength (Clarke 2004). |

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| A Nightmare/ Disclosing to a Church Member | Well telling my family was a nightmare, it was a lot of crying you know thick emotions and crisis... Is much easier with friends than family members. everyone know what is flu, what is diabetes so you take insulin and stuff, but if I say I have HIV is just like when I tell so many I will have to explain so much what`s happening with me and the world, my body, am I dying and what`s the end, it`s just so, well for me I don`t want to do it anymore, is just so if I could tell someone I have HIV okay see you tomorrow. People just have so different ideas so it get really stress and they start crying so you know, so people`s ideas about the disease it could be anything, so is so difficult, just to tell and hope that they know what HIV really is nowadays in Finland but (sh0485ff) | ...then 2002 it was one man in our church, our guardian in the Lord, we confined in him so that he is someone you can rely on, he had to connect me to one nurse that is working at Lagos Island Hospital .... I have come to find out that is very good for you to confined, to disclose to somebody because when you don't disclose it looks you are carrying a heavy load, then when you tell somebody it will be relieved. And each time you are down, that person will be there to help you out. But when you don't tell somebody what is wrong with you even somebody that is sleeping the same house with you, the person might think you are just having ordinary malaria, and will just overlook you, and you will be there dying silently. It is very very good you confine in people that you know will not (aw0071fn) | The perceptions of family members on HIV can determine their reaction when it is disclosure to them; the reaction may be supportive, hostile, or ambivalent (Kimberly, Serovich, & Greene 1995). In NordPol (2007), respondents find it easier to disclose to friends than parents and other relatives, and many prefer to keep their status away from their employers and colleagues. |
| Don't Tell at Workplace/ Disclosure at Workplace | It won`t even come to my mind to tell my work colleagues ... I [don't] know why they will have to know it, so I don`t think why it will affect my work, I don`t know why I would tell any employer. ... but in years, but I don't know what`s gonna happen, and at that point is depending where am working, I might tell my employer, but not if I don`t have like any special reason to do it (sh0485ff) | I will tell them, because if I don't tell them is going to affect me. The way is going to affect me is that if I want to go and take my drug, there is no way it will not affect. Aside of that I don't need to lie to my boss. If he does not want me fine (as0481fn) | PLWHA who disclose their positive status demonstrate normal immune function and are less likely to frequent hospital than those who keep their positive status away from people (Pennebaker, Colder, & Sharp, 1990), this is because suppressing thoughts on difficult experience increases stress-related problem (Greenberg & Stone 1992) |

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| Private Thing/ Public Disclosure | I have this feeling that if I don`t tell people that I have it do something wrong, that am hiding something they have the right to know, but now I have started to realise that is my private thing you know, I don`t need to tell the world (story of the old friend she wanted to disclose to) (sn9975ff). I no longer tell about this at work, but quite a lot of people know, because during my initial shock- phase I was too open about my condition (ms9367ff) | Not only in Nigeria around the world, before you declare your status you are strong then. Now presently people are trying to (ht0484fn). People coming out to say they are HIV positive – declaring their status. That way people know that HIV is actually not a death sentence, I cannot count those who come on air to say their status, and they are doing well – married with kids (tp0389fn). What`s in HIV? We have to public, we have to publicise it so that people will know that is not a deadly disease, so that when they come across it they will know that they don't need to kill their selves before the death come. Is not every-where, but when people say 'HIV oda oh, ahh omo ko ni HIV nlewa' (HIV is not good, someone in our neighbour-hood has HIV) that I will now come in – 'as am here, I am living with it, nothing is wrong with HIV'. People might run away, but I will still say my own.... So I met a lot of people I talk to them about HIV, living with HIV is not the end of the world. I saw boyfriends and girl-friends I talk to them about HIV, 'look at me am living with HIV and healthy'. A lot of them ran away, later on when I was talking they came closer (as0481fn). | In a society that has continued to stigmatise HIV as a disease of deviants, hiding one`s HIV-positive status in Finland has always been used as a survival strategy (Clarke 2004). And many who do not disclose their status believe it does not concern others (Nord-Pol 2007). |
| Drawing People Closer/ Keeping Hope Alive | Sometimes you know, I think that when someone get close to me, or when I tell someone, it actually, more often it affect our relationship in a good way, it makes it deeper, you know they may be start sharing things about their life, and they consider it an honour that I let them know, that I share it with them (sn9975ff) | More people should be encouraged to come out and disclose their status. When you are coming out to disclose your status will keep hope alive. More people should be encouraged to disclose their status that way you are giving more to those who are hiding (tp0389fn) | HIV/AIDS in Finland is still seen in the image of fearful, deadly, and immoral disease which in turn affects it narratives, and the lack of person-al narrative is affecting the acceptance of the disease in the Finnish society. And only 3/400 Body Positive members are willing to give interview with their names and faces (Clarke 2004) |

**Table 21.** The experiences of participants with stigma & discrimination

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| Brutal Treatments at Health Centre / Being Rejected by a Doctor | The medical attendants and doctors in the beginning where much more brutal One doctor once said thait "medical-wise there is no hope for me". This has turned out to be a lie (ms9367ff) | ...a day to my delivery day, the doctor said to me well madam I cannot handle your case. I was heavy, very heavy. The next, we left immediately and then I went home carried my bag, pick a ticket, and took night bus and returned to Lagos ...when I had that baby, it was very fat and healthy, when I travel I said to my husband I want to go and confront this man, to tell him you see this child, that was the child you rejected because I was positive, and my husband said no (aw0071fn) | In Nigeria, one in ten doctors and nurses admit haven refused to care for HIV/AIDS patients (Ogunjuyigbe, Adeyemi & Obiyan 2009) |
| Embarrassments at Health Centre/ No Medical Discriminations | ...like when I was having my daughter, like during labour, of course like it was in all my papers and I could see it affect some of the health care professionals. And usually I can see them go like – it takes time for them to come back '...hey put gloves on shi shi shi' (during daughter`s treatment), that was really terrible (sn9975ff). | They know my status, and they treat me. Different doctors attend to me, they know my status and they treat me. There was a time I had my baby and the placenta took in, they brought the placenta out through what is it called? – Elbow glove (as0481fn) | Many studies have acknowledged the anxiety felt by healthcare workers who come into contact with PLWHA (Hodgson 2006). Improved access to health and social care improves quality of life for PLWHA (Skevington, Norweg & Standage 2010) |

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| Ill Treatments from a Dentist/ Self Stigmatisation | I think like once in a dentist or something, when I went to this small town dentist, well big surprise, he didn`t really know what was going on and he wanted like, well he didn`t know what to like should he like put my appointment like the last one and what protection to use and what to do he was really out of it, he was kind of wired (sh0485ff) | I will even say I am the one stigmatising myself, because even before last year I made up my mind to travel, I thought me being HIV-positive, I won`t be able to travel. I might be denied the visa because of my HIV status. I stigmatise myself, nobody stigmatises me because I felt I might not be able to go beyond the shores of Nigeria just because of my status, I don't know if you get it. At a point when I now got to know that oh, that is not even a problem. The only thing that will make anyone give you special attention is if you test positive to 'Yellow Fever' or whatever is called. I don't remember suffering, having any encounter with stigmatisation (tp0389fn). The stigma and discrimination start with you that is positive, when you discriminate yourself, like now you are tested positive, you start shirring away from people, when you don't discriminate yourself, people will not discriminate you when you are up and doing. Meet with people, if is church, go to church, attend to party, attend to party in a way you look well, but when you discriminating yourself, you stay inside and lock yourself, you are killing yourself. But when you mix with people nobody will know what is wrong with you, and even if you go to occasion you dress better than those who are well (aw0071fn). I walk freely as if nothing is wrong with me (as0481fn) | Some dentists in Canada are reluctant with treating HIV patients (McCarthy, Koval, MacDonald 1999). In Anderson & Spencer (2002, 1347), one informant says "*...I don't let this put me in a box....*" |
| Embarrassment at Church/ Lots of Discrimination | Once a christian mentor I had told me that hiv is God's punishment and the bowl of wrath from the book of revelations. She also told me that there was a form of hiv that has crossed itself with ebola and it spreads by sneezing. A pastor at my church pointed a finger at me from the pulpit. I had brought a male friend of mine to the congregation. The pastor proclaimed that those who are sick should not infect others (ms9367ff) | They discriminate a lot, people look at it as the worst disease that, like if you have committed, like maybe in the olden days they say when you commit any crime, they will through you into the evil forest that is how they are still looking at it. Even some of them if they know that you have it, they will disassociate their selves from you, but the enlightened ones don`t (aw0071fn) | HIV/AIDS is highly stigmatised and discriminated. In 1987 Jonathan Mann a former director of the WHO Global Programme on AIDS, identified HIV/AIDS epidemic with three phases namely: the epidemic of HIV, the epidemic of AIDS, and the epidemic of stigma, discrimination, and denial (Parker & Aggleton 2002) |

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| Rejection from Family Members/ Public Disgrace | Some people startted acting funny, including my mom, who disinfected surfaces I had used or touched, peole feared using the cups, cutlery or toilet I had used. Some did noy want to have anything to do with me. Some judged a lot almost labeling me a tramp…. My mother refuses to get correct information. The only instruction she knows are fron 1980's, my sister, who is a nurse gave them to her. This means disinfecting after me and washing my clothes in a very high temperature separate from others. She doesn't let me do normal functions like drive a moto or a car, like I was handicapped … My family it a bit strange towards me, always wery wary. But the good friends I have don't care (ms9367ff) | My first husband did that, he use to tell people – she is living with HIV this that blaa, blaa, blaa, that never shake me because I look at my front God you are the one am seeing, I look at my back, I see God everywhere around me, so why should I be afraid of human being. If he says anything about me, I will tell those people do I look like someone who has HIV? (as0481fn) | Disclosure of positive status to family members may lead to behavioural change, but counselling of the family members of the PLWHA can bring remarkable improvements (Honarvar 2010). Family members' support and comfort contributes to relieving the impacts of HIV/AIDS (Aga, Kylmä, Nikkonen 2009) |
| Embarrassment from a Hairdresser/ Embarrassing Questions | A wery good friend of mine is a hairdresser. I wondered when she started to dress my hair with cloves on. I asked if she was allergic? She was embarassed, then I realizede why she had done it. She has not done it since (ms9367ff). | I have a lot of friend that will say (name withheld) are you, how did you come across it? They ask me a lot of question – are you flirting around? Are you this are you that? I told them no! Am not flirting around, I never flirt around, I was a virgin when my husband got married to me (as0481fn). Some people you know don't come to you, some will meet me on the road and said (name withheld) they said you have AIDS. I will tell them no, "I don't have AIDS, I have HIV". For me is an opportunity to educate that person, so it gives me an opportunity to educate (ht0484fn) | HIV/AIDS discrimination is one of the greatest obstacles to preventing further infections, and accessing care, support and treatment services that allow PLWHA to live productively (Akinbami et al. 2010). In Cao et al. (2006) study of 601 female migrants in Shanghai, 54.6% of the respondents believe that those who acquired HIV through sex and drug use deserve it. |

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| Living in Bondage/ Isolation | It`s in a way like I don`t behave or act as freely as I would like because am afraid to let people know who I am, I don`t want them to get too close they will find out this terrible secret to me because, I don't want them to, they will find out (sn9975ff) | Normally you are expected to come across such. They will try to isolate one, but is you that will not isolate yourself – I know that nothing is wrong with me. They will call you asawo (prostitute), they will call you a lots of name, but so far you know that you don't do it, why will you be afraid of? (as0481fn) | Social inclusion and perceived improvements of access to health and social care improves quality of life for PLWHA (Skevington, Norweg, Standage 2010) |
| Changed Attitude/ Being Stigmatised and Discriminated at Workplace | My bosses attitude changed along the way. I don't know whether she found out.... Just having top deal with attitudes, at first I got hurt and went home to cry. Lately I have been like: So WHAT! The attitudes are slowly starting too change. At my church I was finally accepted... I feel like God has finally started to pay me back all the years the locusts ate (ms9367ff) | ...stigma has been high, discrimination especially in the work place, but I feel secured. Stigma is still there but it has been reduced, and we can do better.... For me it has reduced especially in health setting, but we can do more in the workplace. At the workplace we still have organisation still sacking people because of their HIV status (ht0484fn) | An interviewee in (Clarke 2004) was refused a job by an occupational health doctor simply because he has HIV. The doctor who see it as his responsibility to protect the company`s finances believes the HIV-positive applicant may need more sick leaves than usual or retire earlier. |
| Less Stress/ Downward Stigma like in TB | I don`t think I see myself very differently, am lucky in a way that when I found out I told all my friends, and no one has treated me any different, so I really haven`t had to struggle with that so much [like many others] (sh0485ff) | I think tuberculosis, I remember one of my relation has tuberculosis, every person use to run away, you understand, you know is a very deadly disease, even missiles you know, since those ones can go down, HIV will still go the same way. The thing is reducing unlike before (aw0071fn) | PLWHA may face social exclusion that includes job and housing discrimination (Clarke 2004). Some of the PLWHA fear that others may discover that they are taking HIV medications (NordPol 2007) |

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| A Call for the Amendment of HIV Laws/ A call for the Implementation of HIV Laws | Participants` conceptions on this can be found in the main text because is too long to fit into the table. | ...is to legalise laws; a lot of laws in Nigeria but is not being implemented. There is a law in the house of assemble, it has not been legalised. We need it to be legalised. (ht0484fn)<br>To have the right, equal right to, but I think the law should actually look at our police officers, in the sense that our police officers should be consecrated (corruption free). The law should back us up in the sense that if you come to stage report, do not talk down on us, do not make jest of us you know is all about the government should improve in education our population. (tp0389fn) | Social inclusion has contributed to the low rate of HIV/AIDS in Finland (Clarke 2004) |

**Table 22.** Impacts of HIV on participants` relationships

| **Themes** | **Finnish Conceptions** | **Nigerian Conceptions** | **Results of earlier research** |
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| Keeping Safe Distance from Men/ Meeting People | Emmm maybe it does affect my social life in a way that maybe am scared of you know not looking for a partner, like getting to know men, you know it`s, I like to keep men like a safe distance maybe as friends you know. Maybe that is all changing as well (sn9975ff). I miss a relationship with the opposite sex (ms9367ff) | I met people, I met a lot of people, people who even have worse effect than I did when I got to know my status, you know that gave me the courage to move on.... I met people – I attended seminars, workshops to learn. It`s very good for me, is very good for me, it helped me to know more people (tp0389fn). And when I got there I saw people older than me and people younger than me and my mind told me you are not alone (ht0484fn) | In Cao et al. (2006) study of the reasons, sources, and types of HIV–related stigma prevalent in rural China, behaviours were primarily associated with fear of the disease rather than with the route of it. |
| Harder Task Finding a Partner/ An Opportunity to Find a Life Partner | ...sometimes I feel that it will make it harder for me to find someone like a man to share (sn9975ff) | I never see that was in my mind. If I see a Muslim, if I see a conk Muslim, if I see a strong Muslim that I want among those living with HIV. I prefer a strong Muslim to someone living with HIV (as0481fn). That support group is where you come, you speak your mind, even those that are looking for husband will come and say there – I want husband oh, I want to marry oh, so they know how they can find somebody or connect you with somebody (aw0071fn). I still have my friends, and added as well (tp0389fn). | HIV/AIDS is self limiting, and makes finding a partner difficult (NordPol 2007) |

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| There is Still a Chance to Fall in Love/ Not a Barrier to Marriage | ...now that I know that because of the medication I know that am not you know dangerous, you know if I fall in love find like a man you know I know that you know he can`t get the disease from me that easily because I have here the virus is so low and everything (sn9975ff) | People are marrying positive, negative people are marrying positive people, positive people are marrying positive, and they are having negative children, and they live happily (aw0071fn) | A recent trial shows that antiretroviral therapy can reduce the chance of one infecting his/her HIV negative partner by up to 96% (WHO 2011) |
| Steady Relationship/ Love without Measure | At the moment am living with a man, we`ve been together for about 5 years. It was lucky for me in a way that he was a friend before, also before I got HIV, and when I found out I told him, and he was still my friend then and took it like everybody else, and then he made the first step, and asked me out so it hasn`t been a problem with him, but I don`t know how it could have worked if I was just like meet someone who would have been interested and then told him.... he knew and then he still decided to have relationship with me, so I have been pretty lucky because I also know some people that don`t want to meet anyone because they don`t want to explain and go through all that, I don`t really have to go all through it, and it looks like am going to be with that guy hopefully for the rest of my life, so I don`t have to put myself in that situation so I don`t know (sh0485ff). | But ever since then I have moved on with my life, and after some years I got married again – after 5 years. It never affect my relationship because I let him understand that…, he does not isolate me. I love him more, more, more, I love him so much, I love him more than my father. He took me for who I am, and for that reason he has not used it to abuse me like my former husband that when we fight he will tell the whole people in the house (neighbours) – do you know what is in this woman? He is not that kind of man, he is a man of my own, my choice, God has give me, and God will not take him away from me, so I will always love him (as0481fn). My husband was carrying me about then, I cannot even, am telling you honestly, that is where you`ll see this vow of marriage working, for better for worse, so I he was always with me. You know already the love was there even before we got married. I married him out of nothing, not because of wealth, just because of that is the way it work, so that is why I always tell people before you get married, don't marry because of material thing, marry because of the love you have for that person (aw0071fn) | |

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| A scapegoat/ Starting a More Permanent Relationship | A scapegoat – like if I will meet a guy, and I will think that well he doesn't really like me, and also I have this disease, of course he doesn't like me you know (the idea pushes you farer away?) yes! (sn9975ff). I no longer find myself attracting ,I am not in a relationship. I find it a high treshold to tell any-body about my disease relationshipwise (ms9367ff) | When I knew my status I ended the relationship I was in, so for me it was not an issue, so right now am married to someone who is not HIV infected, and also I have two children who are not HIV infected. And it does not affect my relationship ...my husband is a true born again person (ht0484fn). I withdrew from having relationship, but am in relationship now, and he is negative (tp0389fn) | |
| Knowing True Friends | | Some of them that have graduated were up and doing – their friend must not die. Some of them that have started working – I have friends I can call friends. We were really getting along (ht0484fn) | |
| A Test of Family Love | | Even then I was staying with my sister that was married with children – three children. And I have to you can imagine the husband was there, she was there, I was there, they did not say go to your house when your TB is cured you can now come back (ht0484fn). The encouragement and love they (her family mem-bers) give me that is what keeps me going, because when they don't give you that love is anoth-er problem (aw0071fn) | Family households should be the first social safety net in all societies, and should demonstrate remarkable strong resilience in time of trouble, but in the case of HIV/AIDS additional support is unavoidable (WHO 2002). |
| Strengthening of Family | | ...life was worth living because of my family, because they were by me, we were together despite the fact that my father had another wife. But none of them run away, in short they were there (ht0484fn). I don't feel lonely at all. People around me are always there for me. It strengthened the love, it strengthened it. Because he is always, even when am out, when it is time for my drug, he always call me, have you taken your drug? That is he cares you know, he wants me to stay alive (aw0071fn) | Care and support should neither be too much or too little. Too much support may be overprotective, and remove the person`s dignity, sense of independence and self-respect, and too little help on the other hand may not provide the support that is needed to ensure that the person eats well and has the strength to resist infection (FAO 2002). |

**Table 23.** Impacts HIV on participants` faith & spirituality

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
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| Drawn Closer to God/ Going Close to God | I have been drawn closer to God. Spiritually I find a lot of comfort in my faith in Jesus, who is the healer and comforter of those who suffer in our time still. All this has drawn me closer to Him and I thank Him and our Heavenly Father for my life, for my daughters life (ms9367ff) | When am down, once I carry my Quran I will be fine. So far I just perform my "Ablution" and I go close to my God I will be fine (as0481fn). After HIV I would say He drew me closer, He drew me closer (tp0389fn). Being positive has made me more closer to God, now am more closer to God, ...Is God`s word. I put on the music, Christian song (aw0071fn) | Fryback and Reinert (1999) study of HIV/AIDS and cancer patients discovered that spirituality is influential to the patients` capacity to cope with the diseases |
| Faith and Hope in God/ Believe You will Make it | I have some good christian friends who pray for me ... I also believe Jesus can and will heal me. And even if he does not, I will always serve Him. The destiny of my family is in Him. I see my future rather lonely. But I don't know what plans God has for me. I have hope, I have faith (ms9367ff) | If you believe you can make it, you will make it. If you have that courage in you that nothing is going to happen, nothing will happen.... You will live on if you have that believe (as0481fn) | |
| There is a Reason for Testing Positive/ Relying on God | I have thought that well maybe there is a reason why I got it, maybe you know God look that she is strong enough to carry it (sn9975ff) | ...my relationship with God has changed in a way that it has helped me to stay positive too in a way, to stay strong rather because I believe within me – "the Bible says as a man think so is he". If I have a notion in me that 'this is it', then I will be living towards that kind of life, but the word of God says "we have power that is not our own", that is why on a daily bases I speak to myself; 'this disease you will not take my life' you know, so that in a way has kept me going strong. But at the same time I have placed my life in God`s hand, I know I don't have to worry about anything. When you put God first in everything, and you have peace of mind, like when I tested positive to HIV (tp0389fn) | In Anderson & Spencer (2002, 1348) one participant who thinks that there are positive sides of having AIDS says, *"If I didn't have AIDS, I'd probably still be out there drinking, drugging, and hurting people. I turned my life around. I gave myself over to the Lord and Jesus Christ."* |
| Troubles Turned Around/ God`s Grace | Faith and joy in Him have turned around all the trouble and made it worthwhile (ms9367ff) | The thing was really disturbing me, really disturbing me, but I keep on trying with God by my side (aw0071fn). For me God has been wonderful in my life, let me use that word. I remember some of us that started together, some of them are late (ht0484fn) | About one-third of the 450 HIV/AIDS patients studied by Szaflarski et al (2006) felt that their life after diagnosis is better than it was before being diagnosed with HIV/AIDS |

# APPENDIX V

**Table 24.** Participants` HIV/AIDS knowledge and awareness

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
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| Knowledge is Power/ Need to Reach Communities | ...well if people are like get education they can like move on with their life, stay healthy... obviously the more information you have is better. I think it will be good if schools could like get a person to come and tell about HIV, probably someone who has it, who has lived with it, but at least in Finland I don`t know how that will be possible, who will go there actually so.... There is still some people who don`t know how you can get HIV (sh0485ff). Education is also something that gives you better prospects in life in a lot of ways. Information, information about it, information you don't die of it, information really that you can`t get it from toilet, you can`t get it from kissing, you can live, and also if you have it, you can live a normal life. Information about it, and education about it, and I really think that`s the best vaccination against this disease. I found out about it, it stopped me from infecting a lot people, a lot of people, and also my sexual behaviour, because I knew about it you know I didn't want anyone else to get it. (sn9975ff). The role of education is very important. We still deal with lots of funny beliefs and superstitions.… As well as educating people how to treat hiv positive right (ms9367ff) | There is need to improve the level of awareness to the grass root. Through media! Adverts, billboards, send people to the communities; counsel people you know hold community rallies just to educate people on what HIV is all about (tp0389fn). Create awareness, let even the school age, small small ones know what HIV and AIDS is, if they have that knowledge, they will know how to take care of themselves. Even your hair you make sure you have your own something (aw0071fn) | Education is probably the greatest empowerment a child deserves (Kelly 2000). And if a person living with HIV gives sex education to students, fear and prejudice will be decreased, and the spirit of constant protective behaviour will be reinforced (Paxton 2002). More than 50% of Nigerians say they cannot shake hand, hug or share the same toilet with PLWHA (Ogunjuyigbe, Adeyemi & Obiyan 2009) |

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| Opening of Thinking Faculty/ Drive to Know | It has somehow opened my thinking you know, in a broader way I understand that you know tragic things happen to people you know is just, is just, is hard to describe but I think somehow it has, it has open my thinking just to higher level, I don`t know if is higher level, but personally I think am a less judgeful person because I have it (sn9975ff) | When I got to know my status, I will say that gave me the drive to want to know what HIV is really all about, you know the *prone and cone* of HIV, and I will tell you the best way I learned is actually through other people`s experience, so from their story you will have the courage to move on. You will know that oh yeah I really need to be strong, actually if this person survived it, then I can survive it. I learnt, went online, read few books. I read "What you need to know about HIV (tp0389fn) | |
| Being Exposed and Informed/ Increase in Knowledge | Now I was, I knew people who had it. I knew quite a lot about it I have read a lot about it ... you know really main thing about this disease is that when you get information about it you see is not that scary, is not that you know very easy to get the disease, is not something you have to be scared of(sn9975ff). To go to Durban for a conference trip and to Dublin too. (ms9367ff) and in a way I get to know more HIV people now (sh0485ff) | ...emm it helped me to improve my knowledge on what the virus is all about.... I attended seminars, workshops to learn. It`s very good for me, is very good for me, it helped me to know more people (tp0389fn). When I knew my status the first thing I did was to find out about the disease that want to kill me. So I went into the internet, then I was at year two at (name of the school withheld). So I went through the internet find out about HIV, find out about organisation in Lagos that I can volunteer for (ht0484fn). | It is necessary to communicate body changes and the social significance of it to young people (WHO 1984), because sexual knowledge improves sexual health behaviours (Herdt & Howe 2007). |
| Sex Education | ...one was maybe 4th grade, then maybe 7th or 8th.... the education I have gotten is not really from school, is from other sources you know is at that time I don't think, I think there was a teacher who really like blushing and you know to just wanna do this, get it done with the students as possible (sn9975ff). I think sex education and returning to fidelity in marriages would keep it abay. Did't they do a program like that in Uganda, which reduced the new infections drasticly? Reducing promiscuiety, proper knowledge how hiv spreads, correct use of condoms and female condoms (ms9367ff) | Be faithful to your spouse, as you know your status, you don't know the status of others, so try and protect yourself and also the other person (tp0389fn). Like my own daughter she is twelve, the other one is seventeen. I educate them, the only thing is to give them the foundation, it does not mean they will go out and start making up themselves. You educate them how to abstain for the young ones, but for the adult ones that are sexually active, you introduce condom (aw0071fn) | To turn around the HIV/AIDS epidemic, young people need to be equipped with the knowledge and skills for protecting themselves against HIV and other STIs (WHO 2002). |

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| Counselling | ...the clinic that tested me said 'now you will get a time from this clinic', and it was like one week after that or something ...and the people who tested me, the woman she came with me to the clinic ...I was offered counselling from a psychologist, I got counselling from doctors ...from professional people saying hey this disease won`t affect your life if you don't want it to affect it. (sn9975ff). I would like more (spiritual) counceling, not judging. Freedom of opinion (ms9367ff) | As a matter of fact she told me don't border just accept it, don't try to fight it such as to know where it came from, just let it go, and I was like fine, I stopped bordering. The doctor advised me, counselled me about thought me about the healthy living things; eating well, positive living advise you know, he taught me a whole lot, and I was like waoh (surprise) is not really a big deal after all (tp0389fn). The doctor here at Lagos then knew about it, he only instruct me – take good care of yourself, eat good food, make sure when you have the baby, you are not going to breast feed the baby (aw0071fn). Finally I met the counsellor, while she counselled me, talk to me that HIV is not the end of the world, you can move on with your life and all that. Now I like to counsel people, if I see, even at Island maternity, if I see people crying I call them and talk to them – why are you crying? I have been living with it for the past 8 years nothing has…, I show them my picture then and my picture now, look at me. All of them will clean their face (as0481fn). I met a wonderful counsellor and she was also positive, although when she told me she was also positive I beg she just dey tell me so that I will feel alright, by the end of the day she invited me to their support group (ht0484fn) | Disclosure of positive status to family members may lead to behavioural change, but counselling of the family members of the PLWHA can bring remarkable improvements (Honarvar 2010) |

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| Promotion of Condoms | I don't think that promoting it is promoting promiscuous sex, it`s promoting something good, you know the world we live in is very sexual. Sex is a natural thing, but also you know a lot of things are sexualised but I really don't think condom is you know, I don't think there is anything bad in it (sn9975ff). If you MUST do it, use a condom. People will always do it anyhow, so free condoms should be available. Giving more kondoms free (ms9367ff). Mainly not good church stuff that not using condom thing like you know save yourself for marriage because many time, just it doesn`t happen so, I think that`s a really big problem especially I think it isn`t like church in many places in Africa or so going around and saying like you know don`t use condom, just don`t have sex and stuffs, it`s just ridiculous.... Yeah, because people have sex.... Well I think that everyone should have a lot of condoms, always, everywhere because you never know. People have sex, in a bit of the moment things happen; it will be nice to have a condom. I don`t believe that you know is a total rubbish that if you give out condoms people will like have more sex, is just people have sex, when they have any way to have sex, it will be nice they use condom, so hand them out everywhere, I think that will be a good idea (sh0485ff) | Condom is good, it protect, is good I will promote it. I talk to people use condom, if you are not ready (as0481fn). There is need to promote condoms. Young people are having sex, despite all our knowing that having it without condom, and they don't know their HIV status, they don't know their partner`s HIV status, so really for me there is need to promote condoms (ht0484fn). Yes, because giving out condoms is in a way saying lets, if you can`t abstain from sex then use the thing. I think with the level of awareness here now, people no longer see it as a way of promoting sex or immorality, no (tp0389fn). Is a good idea, you know Christians go against it, that if you are giving free condom, you are encouraging sex. But since the situation is like this, we cannot sit down and fold our legs. We have sexually active people in the society. Whereby you don't use the male condom, there is female condom for you to use protect yourself. Like those men that has two or three wives, when they get disease if they are not using condom, it start with one person and it goes round the whole women in the house which is not suppose to be so (aw0071fn) | Though recent studies suggest that male circumcision can reduce the risk of acquiring HIV though sex (WHO 2010b), it is the failure of many to see themselves within the high-risk group, and commit to safe sex that facilitates the spread of HIV and STIs (Durojaiye 2011). But abstinence or the use of condoms remain the most effective means of preventing HIV and STIs (WHO 2010b). |

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| Negative Reporting/ Positive Reporting | I think the way is portrayed in media is really not ethical...; the media use it as something you know, like for the wrong intentions the way is portrayed sometimes. the media portray HIV-positive people as evil people who want everyone else to get this disease, yes that`s that`s the point.... Well, the media only tells one part of the story, you know is really not, the media should not say anyone`s name, or anyone`s faces, you know not recognisable facts you know, I really think the media has no social responsibility to to tell people, and also show the two sides of the story (sn9975ff). The only thing I have noticed in the media is people who have infected someone and their faces, names and everything have been like published in the newspapers so that everyone can see that [oh] this person has HIV and has slept with someone – oh my God. So I think that it`s really outrageous how the media works here.... I think the media is doing wrong, what the media is doing is criminal and shouldn`t be allowed.... every HIV person in Finland have been afraid that you know if something happen is my face that is going to be in the newspaper (sh0485ff) | Like in the morning after listening to the news, they say HIV/AIDS is real, something like that. I have forgotten the term they normally use in the morning after listening to the news. So at times you go, there is always some cartoon they put at the Punch (a name of daily tabloid), that is passing the message to people, even some children – at times when you read some cartoon of children, they still use that to pass the message to children. So they are really trying, they are really trying. Even for children you will see some short short firm they show (aw0071fn). They should build their capacity in reporting HIV/AIDS so that they will report issues as they are. Because what they, what people will be listening to, some people don't have how to connect to internet, some don't do anything even maybe buy film to watch on HIV. May be they just tuned the TV and they are talking about HIV/AIDS. It depend on how the message is being related that is when they will listen. So the media have an important role to play. They must build their own capacity then pass the information in the right way and manner (ht0484fn) | It has been established that there is a link between AIDS media coverage and AIDS suicides (Aro et al. 1995). Prior to the confirmation of the first AIDS case in June, 1983, over 50 articles have been published on AIDS painting deadly and fearful picture of the disease like: "*AIDS devours its victims before your very eyes AIDS*" (Clarke 2004, 222). The period was characterised with media '*busy body'*. Journalists were constantly seen around the hospitals in search of the opportunity to take the picture of someone with AIDS (Ibid) |
| A Call for Studies | You know if you have some relative or close person or someone in your work or studies who are interested in it, maybe you start researching hey who are this people, not just bad people, drug addicts, homosexuals, you know prostitutes whatever (sn9975ff) | | |
| A Call for Tackling Malnutrition | Malnutrition sshould be dealt with first in order to gain full benefit from the treatment. My friend works as a missionary in Malawi.She is positive, she has formed hiv- education groups. She says that thebiggest problem is malnutrition.Not hiv/ aids (ms9367ff) | | Where the access to food is either limited or unaffordable, the prevalence of HIV is also alarmingly high (WHO 2002) |

**Table 25.** The experiences of participants at their schools

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| No Disclosure at School/ Confining on School Doctor | Is still very stigmatising and is something I will never tell any of my student fellow student never! I will never tell any teacher in my school (sn9975ff). I don`t want to be public about it, and also I don`t see any reason why people in the university or anyone should know I have HIV, like some people will have like diabetes, I just don`t see like that there will be any connection, why would they have to know about it (sh0485ff)? | And I didn't like to like blow the trumpet – Hey guys am HIV-positive, I didn't have to blow the trumpet, you know I look well, I look healthy, so what I did was when we were going to do our medical check-up, I thought I was scared, really I was scared, then I was like will this deprive me of my education now? I knew to a little extent that being HIV positive does not mean the end. So when I was going to do my medical check-up, the normal procedure when you gain admission into a university, you have to do a medical check-up.... No, no, it does not include a HIV test, is just that the school require your medical history. When I was going to do my, I thought I was scared, I thought it include HIV test, then I was like would this mean I will be denied the admission or something, so what I did was, I met the doctor, I confined in her, I told her, I was, am HIV-positive.... Yeah, yeah, school doctor, so I told her that am HIV positive, she was like "really? waoh! Okay, is no big deal", you know she she she was impressed that I could even speak out, you know, and for me taking the trust in her, someone I have not known before, for me to have confined in her, she felt it was a prize, a big prize to her, so she liked me that much you know, and from time to time she call me "how are you doing, I hope all is well?" We became very close, very very close, funny enough I found out that the medical screening did not include an HIV test. So some people, some people will run away from school (tp0389fn) | People tend to disclose personal information out of distress, and expectance of some kind of benefit (Pennebaker & Beall 1986, Stiles 1987, Greenberg & Stone 1992, Derlega, Metts, Petronio & Margulis 1993, Kalichman, DiMarco, Austin, Luke & DiFonzo, 2003). PLWHA who disclose their positive status demonstrate normal immune function and are less likely to frequent hospital than those who keep their positive status away from people (Pennebaker, Colder & Sharp 1990), while on the other hand suppressing thoughts on difficult experience increases stress-related problem (Greenberg & Stone 1992) |
| Embarrassments at School/ Becoming Famous for Disclosing at School | At school it somehow leaked out that I was positive. Once we had an exercise where we had to take each other from hands, ears, nose... one girl with a large discusted gesture refused to touch me. Once a teacher asked whether I was still capable of learning? I don't know why, but I suspect that she must have been told (ms9367ff) | ...and they never discriminated me, not at all, not even from a student. **In Nigeria?** Like I told you is what you feel, is what you feel. If you are doing something and I don't see what you are doing, for me I don't feel it.... they may talk at the back or whatever, I didn't hear any rumour, even when you entry (name of her school withheld) that time, even to 2010, and ask for my name; people know me... that`s the girl that declared her status in school, you understand? So I was even known for that, I became popular for that (ht0484fn) | Chilisa, Bennell, & Hyde (2001) recommend that University of Botswana should provide a HIV/AIDS friendly environment. And modules should be amended in a way that those students who cannot attend classes always can benefit from the course studies |

| | | | |
|---|---|---|---|
| Normal Life in Campus | | I thank God that am in my final year today. In couple of weeks time I will be writing my final exams. I am done with my project, I lived my normal life in the campus like every other normal student, HIV did not stop me from school, I didn't see that as a challenge. As a matter of fact I leant more when I got to know that am HIV positive (tp0389fn) | Chilisa, Bennell, & Hyde (2001) recommend the promotion of positive living with STI/HIV/AIDS as a coping strategy within and outside campuses |

**Table 26.** Participants` HIV related alteration of study plans

| **Themes** | **Finnish Conceptions** | **Nigerian Conceptions** | **Results of earlier research** |
|---|---|---|---|
| Delayed University Enrolment/ Change of School Choice | Well, I can`t really say because I was using drugs, I wasn't thinking about any university at all, so (sn9975ff) | ...planning to go back to (name of the university withheld) I have to forget about it, so I needed to, my dad said I needed to be in Lagos where I could be close to this people, to talk to, to ask questions whenever I needed to. And then I got a form in another school here in Lagos (tp0389fn) | HIV/AIDS causes double- jeopardy situation that on one hand reduces the quality of education and on the other leaves fewer people able to receive the benefits of learning (WHO 2002). HIV/AIDS attrition reduces university enrolment rates (Chilisa, Bennell, & Hyde 2001) |
| Drop-out for One Semester/ Extra Semester in School | When I got that diagnose then I didn`t know like what was happening, and then I took like one term off, I didn`t do anything just to figure things out (Was there a thought of ending your academic career?) Yeah, because when I just came to my senses, it was just brief period of depression and all that you know after that when I decided that okay life goes on, and I want to do something with my life, then it was just more easier for me to study. I just dropped everything and try to put couple of months. I think that was really good because after that I was like waooh waooh, now I want to start life again (sh0485ff) | An extra semester in school. I was sick, even that time I was going; there was a day I went for exam And inside the exam hall I could not write anything, when the examiner came to my table, I put my head on the table and when he came and torch me I was like "who allowed you in?" I was hot, hot. He was like who allow you in, then I have to get out of the exam hall because I can`t do anything (ht0484fn) | HIV/AIDS affects the demand and supply of education (Kelly 2001). |

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|---|---|---|---|
| Out of School for Four Years/ Nine Years Away from School | Hiv paralized me for 4 more years but the I decided to study even though it was a death sentence those days. I just kind of had faith and hope. Besides I enjoy studying. Decided I would lead my life as normally as I could. Slowly I am working my up. I am thinking of getting a masters degree or studying something else. However I have a permanent full time job now and my wages are relatively good. Sometimes I have been tired but I have never been a quitter and I have generally finished what I start. I Take pride in that (ms9367ff) | Then I have finished the TTC (Teachers` Training College), I have started my NCE (National Certificate of Education), but the illness was coming often and on, then I couldn't continue. So I have to stop education – the NCE. I started with the NCE then I stopped because of constant illness. I started this the NCE course this time around – that was year 2010, I missed school for long i.e. 9 year. I missed school for long, even when I started it was very difficult to adjust (aw0071fn) | Chilisa, Bennell & Hyde (2001) study on the impacts of HIV/AIDS on University of Botswana discovered that HIV/AIDS related stress influences withdrawal from school |
| Learning Disabilities/ Forgetfulness and Request for a Break | Learning disabilities. Due to side effects of the medicine used to treat hiv (ms9367ff) | The bad it (HIV medications) has done is that it makes me to forget easily. Like now we may be talking if it get to a point I will forget what I want to say, and later I will recollect. Because you know this drugs we are taking at times always has effect on your, your, I will say thinking, it makes you forget, but later you will recollect. It got to a point that one day I called our supervisor I said sir, I did not disclose my status, I said sir – I find it very hard to assimilate, how am I going to cope? The man said – if you are going to have a break, of course you will have to (aw0071fn) | In the academic year 1999/2000, University of Botswana asked 132 students to withdraw from school due to poor academic performance, medical and other reasons (Chilisa, Bennell, & Hyde 2001). HIV/AIDS increases absenteeism from classes (Kelly 2001, Chilisa, Bennell, & Hyde 2001), which may also affect academic performance |
| Reduced IQ/ Reading Just Two Days to the Exam | I was a bright student before, I had no trouble remembering nor picturing large entities. Now I am average with hard work. I have trouble remembering and picturing things. I am slow... (ms9367ff) | I can`t read, like if we are going to have exam like next week now, what I will do, I will have to read maybe two days to the exam. I don't read a week before the exam, because I will forget. So I read two day to the exam so that the thing will be fresh on my brain (aw0071fn) | HIV/AIDS has a multiple negative impact on education, especially on her human resource-based development (Gachuhi 1999) |
| Falling Sick after Each Exam | | ...so the stress, and is always very difficult, been HIV-positive is not easy, is very difficult towards the exam is very stressful, and after each exam, I always fall sick, after each semester, to me I don't know about others (aw0071fn) | |

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|---|---|---|---|
| Not Sure/ No Barrier to Studying | I don't think it has [affected me academically]. I have had this disease for a long time, I have had all these years to you know think about it and come to peace with it.... Well now am really very enthusiastic about it (studying), but maybe because I have seen life, and now I really want to, I really have this urge (sn9975ff) | HIV did not stop them from going to school. You can be a graduate, they can work in anywhere; they can work in bank, in any society (as0481fn). At a point when it should have affected my academics work load was when I started drugs (medications) ...initially when I started, the drug make me sick, it makes me drowsy, that is why I said at a point when it should have affected my study I was on break (tp0389fn) | |

**Table 27.** HIV-related motivations for academic pursuits

| **Themes** | **Finnish Conceptions** | **Nigerian Conceptions** | **Results of earlier research** |
|---|---|---|---|
| Hey I Can Do It/ Stronger Drive to Study | ...also if I want to, even if I wouldn't come public, in some way I have, I want to, I want to show me and the rest of the world [most of the world who doesn't know about it], 'hey I can do it', and this disease doesn't stop me (sn9975ff) | HIV-positive or not am not a dull student, HIV-positive or not am not a dull student. So being HIV-positive did not reduce my level of academic strength in any way, I will say my drive became stronger as a matter of fact. I decided to do more to proof to my dad that HIV is not limiting me in any way (tp0389fn) | |
| A Push to Study Fast/ A Push to Study Harder | When I was younger I was really good at school, I have always been the top of my class basically, and then after teenager there was this point that I didn`t, well thought that there is time and I don`t know if I really want to study so fast or maybe I take some years off you know and try to do something lah lah lah, and after the diagnose it kind of like just the speed that process that I want to graduate and do stuff ...like it really pushed me to achieve my goals like to study and start thinking what I will want to do... it just made me study. I don`t see it like affected at least negatively my study or anything, just positively, just to give me the bit of kick that I sometime need (sh0485ff) | So I will say it kind of give me the drive to study harder (tp0389fn) | |

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|---|---|---|---|
| Returning to School | | The foundation of the financial this thing is not strong, that is why I went back to school to upgrade my certificate, so that I can look for a better work. So whereby I didn't do that, in the future am afraid. When I finish now and get a better teaching work, maybe get a work in government Para-status (civil service) at least that is an opportunity. You know when you are no more, when you are not strong, the government will be there for you, but private sector is the one you cannot rely on (aw0071fn) | |
| Switching from Mechanical Engineering to Social Science | | mechanical engineering, so when HIV came into my situation in the sense that is not as if engineering is not a fine course, but I felt like going to talk to people, going to socialise, am going to go into social work, that is why am doing social work now. For me is an opportunity to do so many things, so for me sociology is a fine course.... Am doing part-time again in school, I can be able to work other places that is why am moving up in my degree (ht0484fn) | |

# APPENDIX VI

**Table 28.** Impacts of HIV on work and productivity

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| Medical Records in Safe Hands/ No Barrier to Career Opportunities | I don`t think it would... I think in Finland even if you are working and you have like nurses or doctors at the work place, I can give them the information but if I don`t say yes they can`t give it to the boss, so I don`t know how it could affect me (sh0485ff) | Living with HIV does not mean is the end of the world, it does not mean you cannot be in any position; you can be a leader, you can be anything – so living with HIV is nothing (as0481fn). As far as I am healthy, looking healthy, there is no where I cannot work (aw0071fn) | An interviewee in (Clarke 2004) was refused a job by an occupational health doctor simply because he has HIV. The doctor who see it as his responsibility to protect the company`s finances believes the HIV-positive applicant may need more sick leaves than usual or retire earlier |
| No Negative Effect on Productivity/ Less Thinking | It hasn't affected my productivity at all (sn9975ff) | If someone is working and he is doing well, it makes the person less thinkal – let me use that word. In the sense that their minds are occupied, they are working all that time. So it keeps you busy, you don't have to think any virus in your body (ht0484fn) | Work is an important part of the lives of PLWHA because it providing them access to health care, distracts them from the disease, and allows them to contribute to the society (McReynolds 2001) |
| A Push to Do Something with One`s Life/ Holding on to Big Dreams | I think in my case it just affected it positively. It kind of like give me some goals. I kind of like maybe has more goal to do something. Like I explained earlier, it kind of gave me the boost like to do something with my life, and not just to hang around not just doing something. It`s kind of in some way given me some reason with HIV to do things. Even though that after I found out I have been more driven to do stuffs (sh0485ff) | ...for me I still want to be one of the best designers in the world, I still want to learn fashion designing, ...you don't say because I have a virus okay let me not be exact what am going to do, whatever profession you do, going to school is not the only thing, whatever profession they want to do they should do it very well (ht0484fn) | In Anderson & Spencer (2002, 1347), the self help that served as healing balm is expressed like this: "It's a sickness, but in my mind I don't think that I got it. Because if you think about having HIV, it comes down more on you. It's more like a mind game. To try and stay alive is that you don't even think about it. It's not in the mind" |

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|---|---|---|---|
| A Career on Educating People about HIV | | Fortunately for me, the job that I have is actually to educate people on what HIV is all about, that is why I got a lot of this training last week in Abuja…. I am opportune to be living with it, when I am able to know actually the problems, but how about those in the rural areas who are not educated or talked to about the whole thing. In matter of weeks to come, I will be going to Osun State to create more awareness (tp0389fn). When I volunteered for one organisation, I was a week for their programme, and present their 'AIDS Online', the TV series and a radio programme live. That was my first major appearance that was 2005, and talking about HIV (ht0484fn) | Gerouki (2010, 10) stated that, "the school age is regarded as a very appropriate time for children to receive the first stimuli that will contribute to their proper psychosexual development". And if a person living with HIV gives sex education to students, fear and prejudice will be decreased, and the spirit of constant protective behaviour will be reinforced (Paxton 2002) |
| Going Extra Miles | | I also have a youth project that I do, so I do what people see extraordinary (ht0484fn) | |
| Reduced Capacity to Work/ Becoming Less Productive | The tiredness and neurological side- effects affect my productivity, of course. I have estimated that I am 75% from normal. But used well and wisely, this is enough. At employee´s health care I have told my doctor and they see no implication why I should not continue working. But as I said, times have changed. People have seen me in relatively good health for nearly 20 years now. They saw me give birth to a hiv- negative child, they saw me study, they saw me graduate and now with a steady job (ms9367ff) | Like now I can`t do any strenuous work, I can`t do anything that is very strenuous. I work less now. I don't work as I use to work, because when I work as I use to work before, it will weigh me down, to avoid that I have to reduce my [work] (aw0071fn) | The earlier a person tests positive to HIV, the more the disease has affected his/her ability to work or study (NordPol 2007) |
| Sleeping at Work / Limited Chances for Working | When seated, doing nothing I often easily fall asleep, which is embarassing at important meetings (ms9367ff) | Each day of my life I want to grow higher, that is why I use to, am struggling to still contribute in the family, to see the well being of the family, I did not abandon it for the man alone, even if is hundred naira is something in the family. You know when as we are positive if we don't have something that you are doing, giving you money and the load is on one person [one spouse] alone, you know how men at time, it won`t be very good (aw0071fn) | HIV/AIDS greatly affect workers and their productivity (WHO 2002), but with the use of medications people living with HIV are kept well and productive for a long time (WHO 2010b) |

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|---|---|---|---|
| Somehow Discriminated at Workplace/ Losing One`s Job | At work I suffered surprisingly little. I have had two jobs, where they knew about my status. In the firts one my boss was ok about it, in the second one I was discriminated for this and other reasons. There are not many hiv- positive practising. My employee´s health care unit said that I was the firts one there. They thanked me for being honest. Together we follow my ability to work under such streass wery closely (ms9367ff). | I called the woman I told her please every last Wednesday or Thursday I will be going to the hospital for medical check-up, I didn't tell her my status. The husband of the woman accepted so the following day I came to work. She came to me, "madam, I have thought about this your medical check-up, I don't think it will work, unless you will leave it oh", immediately I said madam, I cannot compromise work with my health (aw0071fn) | Work discrimination is perhaps the greatest challenge for PLWHA in Finland (Clarke 2004). One informant in Anderson & Spencer (2002, 1346) who will not want the disease affect his working life says "I have to pay attention to it. It's serious enough to put me out of work." |
| Economic Hardship | | Is very difficult for average Nigerian talkless of somebody. Last week I travelled, I when to solicited for my children school fees .... Things are not as it was for my husband, so one wanted to take WAEC, because he is owing they did not allow him to take mock, and the whole thing was on me – thinking, God helped me I did not break down (aw0071fn) | Koopman et al. (2000) study of relationships of perceived stress to coping, attachment and social support among HIV-positive persons discovered that personal income has effect on the level of one`s HIV stress. |

**Table 29.** Participants` fears and worries due to their HIV-positive status

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| Worries about Twelve Pills a Day/ Fear of Taking Pills for Life | Deep down I have wondered how long is my body going to support all these drugs. 12 pills a day I am taking (ms9367ff) | ARV is actually the thing for a lifetime, the medication you are to take for a lifetime, so that in a way scare people (tp0389fn). Take drugs everyday is somehow, but is my life, I have to take it (as0481fn) | |
| Worries About Coping with Side-effects | Due to heavy side effects of the drugs my body might not be able to cope just as long. But then again it might (ms9367ff) | | |
| Standing Out | I think in Finland is so difficult, the number in Finland is not so much like in UK, there is not so much knowledge, people don`t have so much information, people don`t know someone with HIV, so I think the view here is like drugs, people who use needles.... this country is still so small people will recognise you (sh0485ff) | | According to the UN-AIDS/WHO (2008) epidemiological fact sheet, the prevalence of HIV/AIDS in Finland is relatively low (about 2600) when compared with other countries |

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|---|---|---|---|
| Fear that People will Find out | ...it has brought a lot of you know fear that people will find out. I have this worry that somehow someday people somewhere people will find out about this disease I will be in a situation where I have to defend myself. Like defend myself like defend my right to be in that thing – position I mean (sn9975ff) | | Opportunities for a bright future may be lost or destroyed by HIV/AIDS infection (Gachuhi 1999) |
| Fears Relating to Being Hired | I think that`s the – I think maybe if in some way someone will hiring me will find out about, some way (sn9975ff) | | |
| Worry about Disclosing to a Daughter Someday | My daughter is a year and half, sometime I wonder what would she say, what would she think one day when I tell her about this (sn9975ff) | | |
| Fear that a Social Worker will not keep to Non-Disclosure Obligation | At my recent job one of my collegues is a social worker, who knew me and my life´s history, my illness etc. from the time I was a client at the social services. When I realized that she was going to be my collegue, I went to her saying that I trust her to keep my secrets, She said that she is under non- disclosure obligation and that I should not worry. But I know how the collegues gossip about customers and work mates (ms9367ff) | | Lack of confidentiality prevents HIV-positive people from seeking support. Even some of the PLWHA have problem trusting one another (Issiaka et al. 2001) |
| Fear of Being Rejected | This disease is something I think or am afraid is probably just my fright that says that if people find out they will reject me, is probably not true I know that you know intelligent people most likely they won`t (sn9975ff) | | Solitude is a problem for PLWHA. And according to NordPol (2007), 59% of respondents believe they are alone despite the fact that they prefer people`s company |
| Distorted Future | I probably still have sometimes that I think that when I look at life through the disease I think that maybe it can`t offer me like this full life (sn9975ff) | | HIV/AIDS has strong impacts on people`s ability to plan for the future (Clarke 2004) |

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|---|---|---|---|
| No Cure in Sight | I think it will take a long long long time before you find a way to get rid of, to be cured totally of the disease, probably even longer before you get vaccination for it (sn9975ff)... but not in the near future, I don`t think so (sh0485ff) | | In Anderson & Spencer (2002, 1345) a participant expressed the lack of hope for cure this way: *"There is no cure and I don't see any coming either."* |
| Afraid of Nothing | | Nothing to, why would I fear? Maybe at worst they won`t want to talk to me. Do I even want to make someone a friend? Must I make friend with people? I make friend with people that love me. I will have children like normal person, since there is solution, there is nothing to worry about (as0481fn). There is nothing to be afraid of because now am so sure I have seen people, positive married to negative spouse, and they have negative children (tp0389fn). I don't even have fear because I know my right. If I get an employment now, and the person sack me because am [positive], if it happen the person sack me, I will sue him (aw0071fn) | |

**Table 30.** Hopes expressed by participants despite their HIV-positive status

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| Hope for Fulfilled Life/ Hope for a Bright Future | Good life, happy life, someday. I enjoy my study; I think I will enjoy my work someday. I have a beautiful daughter, am quite sure someday I will have husband or you know someone to share this life with ...I think I would be independent financial independent (sn9975ff) | Still having the drive to pursue my career gives me hope (tp0389fn). My future is very bright, and I long to see my children`s children if God permits because I know He is the only one that has the final say (aw0071fn) | Hope has proven to be an<br>important resource for responding positively to HIV/AIDS (Kelly 2007) |
| Hope for Better Drugs and Cure/ Hope for Cure | No! (I don`t think that the disease will kill me one day) Especially because in 10 years the drugs, everything have developed so much, so God knows what in 10 or 15 years in the future, everyone working to find better drugs maybe cure (sh0485ff). Even better drugs will come along. Life expectancy will be longer and hopefully side effects will be lighter ...I have a hunch, the treatment will come up from nature or animals, just as it did with tuberculosis (ms9367ff) | I know one day it will go! It will surely go; the drug that will clear it away will soon come, so why would I need to worry myself? That is my believe. Formerly HIV did not have any drug, initially, HIV did not have any drug, but I know very soon they will find a cure drug for it. We know very soon there will be a solution. I know God has solution for everything. I know very soon there will be a way to it, there will be a solution, there will be a way out, there will be a drug that will clear it totally. Nothing in this life there is no solution, there is solution for everything only death that does not have solution (as0481fn). In the future I know the cure will come, and that is what we are praying for God to keep us alive let us experience the cure (aw0071fn). | In Anderson & Spencer (2002, 1345) a participant expressed the view of possible cure in these ways: *"I'm just happy to be here now and hope to be here when they find something."* |
| Hope of Medications for All | **...**it will be possible one day for all the HIV people to get medication (sn9975ff) | | And since HIV treatments have helped to improved the work performance and decreased absenteeism from work (Beard, Feeley, Rosen 2009) |

# APPENDIX VII

**Table 31.** Transformations in participants due to new self-perceptions

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| New Perspective to Life/ New Way of Seeing Things | Obviously someone die at some point but when you get some reminder that you are going to die at some point, then it can like put new perspective... (sh0485ff) | It has changed for the better (my way of seeing things), it has changed completely (aw0071fn) | |
| Realising that Life has no Duplicate/ Attention to Health | I realised that I only have this one life that I need to live and I need to live it as good as I can (sn9975ff) | By testing positive drew my attention to my health, I stay healthy, I care about where I sleep not expose myself to mosquito bite, because malaria is a killer disease – it kill faster than HIV (tp0389fn) | People living with AIDS can control the progression of the disease by caring for themselves (Anderson & Spencer 2002) |
| Sustainable Living/ Becoming a Better cook | I know that I had to take it more easy, I want to because in the same time also I realise that work isn`t my life or money or nothing like that but I always little hippy so I think even without it I think I would more chill, not so! I don`t think about productivity so much, I just hope that I can find a job that help to save the world in some way, but am not really interested about money and everything like how the world work, so! (sh0485ff) | HIV made me a better cook, HIV made me a better cook, because I use to, am like I feed on junk, bread & tea, bread & sardine, but when I tested positive to HIV, I got to know the need to eat well, then I learnt to cook, and I improved. I cook my meal, I cook myself and I enjoy doing it (tp0389fn) | Many people today think sleep is a waste of time, but the reality is that it isn't. It is extremely valuable to our ability to perform and carry out our life functions (Hardinge 2008). In NordPol (2007), respondents started eating healthier after they tested positive. |
| Transformation into a Better Person | I think maybe it has made me you know a little bit better person than I will be without it, because maybe I don`t judge other people easily(sn9975ff) | Things that are good in testing positive to HIV are many. If you have been living a wayward life, it will change. If emm okay, if you are someone that always quarrel so much, it will change. And the way you see things will change (aw0071fn) | In Anderson & Spencer (2002, 1348) one participant who thinks that there are positive side to having AIDS says, *"If I didn't have AIDS, I'd probably still be out there drinking, drugging, and hurting people. I turned my life around. I gave myself over to the Lord and Jesus Christ."* |

| | | | |
|---|---|---|---|
| A Warrior Princess/ Voluntarily Joining of Anti-AIDS Club | As a warrior princess (ms9367ff) | I see them I was like I don't have any business let me just face my study and just get out of the school. When I knew my status, I have to then voluntarily join the anti-AIDS club (ht0484fn) | In Anderson & Spencer (2002, 1346), one participant expressed his self image and hopes this way: *"I'm a fighter and I'm never going to give up until they come up with a cure for this."* |
| Additional Privilege | | Am a kind of privileged meeting with some people in high places. Imagine meeting with the MD (Managing Director) of NTA (National Television of Nigeria), MD of Chevron, ordinarily I wouldn't have even if I am working, in a good day I wouldn't walk up to the MD`s office and say I want to see him. So for me that is an advantage (ht0484fn). I will say being HIV positive opened doors of opportunities. I even wonder within me that if I had not tested positive, I won`t be where I am. Okay for instance, my dad gives me extra attention in the sense that I do not lack anything, I do not lack anything. Last year I was opportune to travel to (name of the country withheld), and am very very sure he wouldn't have sponsored that trip. But because I said please this will make me happy, he accepted. So HIV has not limited me in any way (tp0389fn) | About one-third of the 450 HIV/AIDS patients studied by Szaflarski et al (2006) felt that their life after diagnosis is better than it was before being diagnosed with the disease |
| Planning One`s Life | | There is many positive things about it. You will then need to plan your life if you are the one that don't use to plan your life before, you start planning for it. If you have children you will start planning for those children in case if anything happen the children will be comfortable where ever they are. It helps you to plan your life (aw0071fn) | Nedley (2011) listed ten characteristics they share which includes: staying active, eating lots of fruits and vegetables, limited or no meat & processed foods, drinking plenty of water, no smoking, limited calorie intake, limited/ no alcohol intake, have active social network, pursue a spiritual path, and have a sense of purpose in life. |
| Time Consciousness | | Like now, am always time conscious, any place I am now, even without my time, if that time get to time to take my drug, I will feel somehow in my body, then I will remember that I have to take my this thing [pills]. And now I always keep to time, whatever am doing, I keep to time (aw0071fn) | UT Southwestern Medical Centre study shows that weekend sleep-ins which may mix-up an individual`s daily rhythms do more harm than good (YLE September 2012d). |

| | | | |
|---|---|---|---|
| Little or No Change | | It never changed anything, and it will never, the only thing that has changed in my life is the drug (as0481fn) | |

**Table 32.** Reformed lifestyles due to living with HIV

| Themes | Finnish Conceptions | Nigerian Conceptions | Results of earlier research |
|---|---|---|---|
| A Wake-up Call/ Changing Old Habits | I try to eat healthy, and I stopped smoking cigarette, and I try to exercise but well try, mean while my schedule at the moment is so busy, yeah obviously I have to think what do I do for my body because is more frail than normal people, this is not easy but I have to be more careful(sh0485ff) | ...and now I eat fruits more than before, I can`t go a day without fruit, and I eat more of vegetable (tp0389fn). Like mineral (soft drink), I notice if I take mineral, I will start purging. I have stopped it completely. I noticed beans, if I don't eat beans early sometime, I find it difficult to sleep, the thing will not digest very well, then I stopped that. You know, many other things (aw0071fn). People should exercise, eating more balanced diet, emm taking enough water, taking fruits, for me that is how I live. Then having a good fresher life, let me use that word in the sense that most of us are at the habit of people can dictate for us (ht0484fn) | In addition to HIV treatments, PLWHA often need counselling and psychosocial support, access to good nutrition, safe water and basic hygiene to improve their quality of life (WHO 2010b)<br>In addition to HIV treatments, PLWHA often need counselling and psychosocial support, access to good nutrition, safe water and basic hygiene to improve their quality of life (WHO 2010b) |
| Positive Living/ Healthful Living | I take more care of my health now that I know it is not a mortal disease... I don't smoke, drink or party. I do sports and try to eat and sleep well. I keep my spirits high… Swimming, gym, cycling, aerobics, pilates and healthier diet. Going to theatre. Resting…(ms9367ff) | I eat fruits now before I don't like fruits. I don't like taking a lot of water, I do that now. I don't like exercising or walking too long, I do that now. That is the only thing, all other things my life still remain the same (ht0484fn). Relax (tp0389fn) | FAO (2002) advices that PLWHA should take extra rest, stress less, keep positive attitude, take light exercise, seek counselling, accept help, quit smoking, avoid non-prescribed drugs, and refrain from alcohol which apart from being harmful to the body, unprotected sex occurs under its influence |
| Controlling Appetite/ Carefulness in Choosing What to Eat | I love sweet things, but then I try to, to not to eat that very much, sometimes I try harder, sometimes I just let myself eat whatever I want, but it`s almost like I try to eat quite healthily (sn9975ff) | Now I am, I am 100% careful what I take, and the environment, even my children at home, I protect them because I wouldn't want the situation where I will be down or my husband; is better for one, for me that have already gotten it to be down than others. It (HIV) helps you to change your lifestyle (aw0071fn) | Though in NordPol (2007) the respondents still smoke as much as they were previously smoking, but they have reduced alcohol consumption |

| | | | |
|---|---|---|---|
| Less Stress | I think if I need I gonna take some time out. I don`t stress so much, I don`t push so much usually, like if I have really difficult in school like earlier too much to do, I just take time out if I need to, am not so hard on myself you know (sh0485ff) | I try to reduce my working so that I will have enough rest. Very very careful with whatever I do. Even when working, at times when you are working your body system will tell you, you are tied. Immediately I feel so I will stop whatever am doing, am very careful. At least that one will give me time to rest, to have enough rest (aw0071fn) | |
| Good Hygiene/ An End to Sharing Shape Objects | I try to take really good care of my teeth... (sn9975ff) | What has changed in my life, in the past I just, if you have razor blade you have used before, I just borrow it from you. Like I will go to any of my sisters, the eyes lips they have used before I will borrow. Tooth brush I can use any of my sisters` okay you are my sister, you don't have anything, I will use it. You know many thing, even the way of doing my hair, I have my own this thing, before I can go with anything, but now am very conscious of it, I don't want to infect somebody else, I don't want them to infect me (aw0071fn) | Hand washing prevents diarrhea and other communicable diseases, and it requires only about 20 seconds at each time (Nedley 2011) |
| The Biggest Reason not to do Drugs Again | The biggest main thing is that is one more reason for me not to try using drugs again (sn9975ff) | | In NordPol (2007), a large number of those who tested positive after 2002 indulge in unprotected sex under the influence of alcohol and drugs |
| Strict Temperance | I live a very very normal life, and except that I don`t drink you know most Finnish people drink, I don`t drink at all, never, I don`t think I will ever again in my, the rest of my life.... Drug free, alcohol free (sn9975ff). I quit smoking some years ago (sh0485ff) | | Alcohol consumption among other social norms often hinders efforts on curbing the spread of HIV (NordPol 2007) |

| | | | |
|---|---|---|---|
| Balanced Diet | I eat quite healthily, I try to stay healthy... I try to eat like well balanced, I try to eat fruits, vegetables, meat, potatoes, like you know we have this pyramid (i.e. food pyramid that guide people in selecting and making their food choices) in Finland (sn9975ff). Well the fact is that if you eat healthy you live healthy, you live like is with like diabetes and like with all normal people also you live long if you live healthy, obviously, the HIV is also important to eat healthy (sh0485ff) | | Balanced nutrition is one of the most important aspects of HIV/AIDS counselling. Because it sustains strength and body weight, replacing lost vitamins and minerals, and improves the ability of the immune system to fight diseases (FAO 2002) |
| Remaining a Vegetarian | I have been vegetarian for about 15 years, so I eat quite healthy anyway (sh0485ff) | | Beside fruits and vegetables, legumes, nuts, and wholesome (unrefined) grains have also been found to carry heart disease and cancer risks reduction properties (Hardinge 2008) |
| Outdoor Exercise | I exercise, I go out, move my dog, I like walking (sn9975ff) ... and I try to exercise but well try, mean while my schedule at the moment is so busy.... (sho485ff) | | those who exercised for an average of 92 min per week or 15 min a day, have a 14% reduced risk of all-cause mortality, while individuals who are inactive have a 17% increased risk of mortality (Wen et al 2011) |
| Avoidance of Opportunistic Infections | | ...those living positively with HIV, taking myself for an example, I try as much as possible to avoid any opportunistic infection (tp0389fn). Ever since I got it I don't go to saloon, but if truly I want to go to saloon, I will have my own (as0481fn) | Avoid coughing or sneezing into your hand, but maybe your elbow or where you will not easily spread it. And when dirty keep your hands away from your face (Nedley 2011) |

| | | | |
|---|---|---|---|
| Staying in a Mosquito Free Environment | | I will say though am not a very strict person, but I will tell you I can`t stay anywhere where I feel there are mosquitoes. In fact I don't want to get infected by malaria; you know I pay more attention to my surrounding, you know keep the place mosquito free if it is possible. But you know even living in Nigeria, that cannot be 100% attend, but I try as much as possible. I always sleep under mosquito treated net because I don't want to be infected be malaria (tp0389fn) | People living with HIV/AIDS (PLWHA) are at an increased risk of clinical malaria, severe illness, hospitalization, and death (NMFS 2011) |

# APPENDIX VIII

Here include the Concept Map outcomes in text format; while in most cases the participants were directly quoted, in some the conceptions were paraphrased to fit into the Concept Map, and there are slight changes when compared with the main Concept Maps in the text.

**KNOWLEDGE AND UNDERSTANDINGS OF THE FINNISH PARTICIPANTS ON HIV/AIDS**

| | | |
|---|---|---|
| HIV/AIDS | is now conceived | not to be that fearful |
| HIV/AIDS | positive conceptions includes | life restorer |
| HIV/AIDS | was initially conceived as | no hope at all |
| HIV/AIDS | was initially conceived as | gay disease |
| HIV/AIDS | conceived origins includes | what existed in ancient Egypt |
| HIV/AIDS | is conceived | no more as a death sentence |
| HIV/AIDS | was initially conceived as | social recluse |
| HIV/AIDS | negative conceptions includes | limited lifespan |
| HIV/AIDS | negative conceptions includes | stigma of shame |
| HIV/AIDS | conceived origins includes | maybe from monkeys |
| HIV/AIDS | is now conceived | as not that contagious |
| HIV/AIDS | was initially conceived as | something scary |
| HIV/AIDS | conceived origins includes | a virus that existed in the tropics |
| HIV/AIDS | positive conceptions includes | HIV-negative children |
| HIV/AIDS | positive conceptions includes | one more reason not to start using drugs again |
| HIV/AIDS | negative conceptions includes | people suffering and dying |
| HIV/AIDS | is now conceived | as a constant reminder that you are going to die at some point |
| HIV/AIDS | negative conceptions includes | restricted travelling |
| HIV/AIDS | negative conceptions includes | a fast spreading disease |
| HIV/AIDS | is now conceived | as not necessarily AIDS |
| HIV/AIDS | was initially conceived as | something dirty |
| HIV/AIDS | is now conceived | no more as something dirty |
| HIV/AIDS | positive conceptions includes | not a death sentence |
| HIV/AIDS | was initially conceived as | death sentence |
| HIV/AIDS | negative conceptions includes | constant reminder of death |
| HIV/AIDS | negative conceptions includes | something black, red, white and round |
| HIV/AIDS | negative conceptions includes | something linked to gay sex, IV-drugs and promiscuity |
| HIV/AIDS | is now conceived | as a disease without a sure vaccine |
| HIV/AIDS | negative conceptions includes | being always seen as the criminal |
| HIV/AIDS | was initially conceived as | kaposi`s sarcoma in the face |
| HIV/AIDS | is now conceived | as only a chronic disease |
| HIV/AIDS | was initially conceived as | an opportunity to give-up all responsibilities |
| HIV/AIDS | negative conceptions includes | a stigma that may slowly change |
| HIV/AIDS | was initially conceived as | something that happens in Africa |
| HIV/AIDS | was initially conceived as | something far |

**KNOWLEDGE AND UNDERSTANDINGS OF NIGERIAN PARTICIPANTS ON HIV/AIDS**

| | | |
|---|---|---|
| HIV/AIDS | is now conceived as | unnecessary struggles |
| HIV/AIDS | conceived origins includes | unnecessary |
| HIV/AIDS | positive conceptions includes | saving a sister's life |
| HIV/AIDS | is now conceived as | a disease without a sure vaccine |
| HIV/AIDS | positive conceptions includes | normal life |
| HIV/AIDS | is now conceived as | no more a death sentence |
| HIV/AIDS | conceived origins includes | from western world |
| HIV/AIDS | was initially conceived as | something not made for them |
| HIV/AIDS | negative conception includes | a disease that affects one mentally |
| HIV/AIDS | negative conception includes | negative labelling |
| HIV/AIDS | negative conception includes | husbands dying or running away |
| HIV/AIDS | positive conceptions includes | HIV-negative children |
| HIV/AIDS | was initially conceived as | a deadly disease |
| HIV/AIDS | is now conceived as: God to increase the | not that contagious, punishment from fear of God, from western world to Africa through expatriates |
| HIV/AIDS | is now conceived as | only a chronic disease |
| HIV/AIDS | positive conceptions includes | being healthier than those who are not sick |
| HIV/AIDS | conceived origins includes | punishment from God |
| HIV/AIDS | conceived origins includes | from time immemorial |
| HIV/AIDS | is now conceived as | not necessarily AIDS |
| HIV/AIDS | positive conceptions includes | encouragement for fidelity |
| HIV/AIDS | is now conceived as | only a severe fever |
| HIV/AIDS | was unknown to me until | I tested positive |

**EMOTIONAL/ MENTAL HEALTH IMPACTS OF HIV ON FINNISH PARTICIPANTS**

| | | |
|---|---|---|
| HIV | positive result means: | death as the first impression |
| HIV | coping strategies includes: | support group meetings |
| HIV | positive result means: | going for a second test |
| HIV | positive result means: | rocky period |
| HIV | led to my | having difficulty in picture complex images |
| HIV | screening | should be done before it is too late |
| HIV | positive result means: | death or something similar |
| HIV | positive status acceptance | led to identity crisis |
| HIV | positive result means: | distorted self image |
| HIV | coping strategies includes: | deciding that I want to live |
| HIV | positive result means: | what`s the point of like going over things |
| HIV | coping strategies includes: | having long time relationship with someone to talk to |
| HIV | screening | helps in avoiding catastrophic situation |
| HIV | coping strategies includes: | talking to people |

| | | |
|---|---|---|
| HIV | led to my | requiring extra effort to stay focused |
| HIV | positive result means: | permanent stamp |
| HIV | positive result means: | thoughts of going to die soon, younger |
| HIV | positive status acceptance | was after a second test |
| HIV | screening | helps in dictating the virus as early as possible |
| HIV | emotional stress includes: | feeling is a big issue sometimes |
| HIV | emotional stress includes: | seeing one`s future rather lonely |
| HIV | positive result means: | push to study in order to achieve goals |
| HIV | emotional stress includes: | feeling unattractive and old, even though people tell you otherwise |
| HIV | positive result means: | life going back to normal |
| HIV | positive result means: | undisclosable big dark cloud bearded for 6 months |
| HIV | emotional stress includes: | thinking it has... inside my head |
| HIV | positive result means: | thoughts of dying soon |
| HIV | coping strategies includes: | feeling you are not alone |
| HIV | positive result means: | shock |
| HIV | coping strategies includes: | coming to peace with it |
| HIV | positive result means: | starting to think of what to do |
| HIV | emotional stress includes: | the future not looking great to look forward to it |
| HIV | positive result means: | Doctor not offering a chair |
| HIV | positive result means: | being hurt by the disease |
| HIV | positive result means: | becoming devastated |
| HIV | positive result means: | not wanting to talk to people |
| HIV | positive status acceptance | means something I will have to live with the rest of my life |
| HIV | positive result means: | new perspective to life |
| HIV | positive result means: | sickness has happened |
| HIV | emotional stress includes: | prison of shame is inside |
| HIV | positive result means: | loss of hope |
| HIV | coping strategies includes: | helping other |
| HIV | coping strategies includes: | starting to consider myself as a normal human being |
| HIV | emotional stress includes: | feel lonely and sad |
| HIV | positive result means: | becoming confused |
| HIV | positive result means: | recovering from lousiness |
| HIV | positive result means: | wanting to do something with my life |
| HIV | positive status acceptance | is mentally hard |
| HIV | positive result means: | additional sorrow |
| HIV | coping strategies includes: | telling other PLWHA - hey I have lived with it for 12 years you know; it hasn’t really affected my life that much |
| HIV | coping strategies includes: | not think about it |
| HIV | emotional stress includes: | drinking heavily for 6 months |
| HIV | positive status acceptance | loss of goals in life |
| HIV | emotional stress includes: | short time of being weary |
| HIV | positive result means: | drinking |
| HIV | positive result means: | a reminder that you are going to die at some point |

| | | |
|---|---|---|
| HIV | emotional stress includes: | feelings of hiding from people |
| HIV | emotional stress includes: | several suicide attempts |
| HIV | led to my | becoming a bit slower |
| HIV | coping strategies includes: | fighting back |
| HIV | positive result means: | what has happened has happened |
| HIV | emotional stress includes: | suicide thoughts |
| HIV | coping strategies includes: | a lot of support from people that had it longer than me |
| HIV | positive result means: | just walking around |
| HIV | emotional stress includes: | being depressed |
| HIV | coping strategies includes: | believing that life is worth living and stuffs |
| HIV | coping strategies includes: | working against your [negative] feelings |
| HIV | positive result means: | bad news made worse |
| HIV | coping strategies includes: | seeing the disease is not part of my everyday life |
| HIV | positive result means: | thinking I have few years to live |
| HIV | coping strategies includes: | not thinking about it often |
| HIV | led to my | trouble remembering |
| HIV | emotional stress includes: | the creation of barrier inside |
| HIV | positive result means: | this is it! |
| HIV | positive result means: | a short period of self pity |
| HIV | positive result means: | not telling any one |
| HIV | positive result means: | starting to take care of yourself |
| HIV | emotional stress includes: | feeling like a social recluse |
| HIV | coping strategies includes: | deciding that okay now it is time to get up from the bed |
| HIV | emotional stress includes: | feeling guilty for not doing the right thing to protect one`s self |
| HIV | positive result means: | no big deal |
| HIV | coping strategies includes: | living to be admired |
| HIV | positive result means: | increased responsibility |
| HIV | coping strategies includes: | living in a way that it does not stop you from doing thing |
| HIV | positive result means: | limited social life |
| HIV | coping strategies includes: | rebuilding self consciousness |
| HIV | positive status acceptance | accepting what we cannot change |
| HIV | emotional stress includes: | feeling it`s kind of own fault |

**EMOTIONAL/ MENTAL HEALTH IMPACTS OF HIV ON NIGERIAN PARTICIPANTS**

| | | |
|---|---|---|
| HIV | coping strategies includes: | sharing our different experiences and challenges with PLWH |
| HIV | coping strategies includes: | moving on with your life |
| HIV | positive result means: | thinking about the baby in the womb |
| HIV | positive result means: | being cheated a bit |
| HIV | coping strategies includes: | taking of minerals and vitamin |
| HIV | coping strategies includes: | drinking a lot of water |

| | | |
|---|---|---|
| HIV | coping strategies includes: | identifying myself just like someone with normal illness |
| HIV | emotional stress includes: | hardship due to being less productive |
| HIV | coping strategies includes: | praying |
| HIV | positive result means: | not talking to people at school |
| HIV | coping strategies includes: | working |
| HIV | emotional stress includes: | being pushed out of a matrimonial home while my baby was 2 weeks old |
| HIV | coping strategies includes: | receiving soft loan |
| HIV | coping strategies includes: | helping others |
| HIV | coping strategies includes: | not thinking |
| HIV | screening | helps in discovering the virus early |
| HIV | positive result means: | unscarred |
| HIV | coping strategies includes: | being happy always |
| HIV | screening | was done every 6 months |
| HIV | coping strategies includes: | believing that nothing is wrong |
| HIV | positive result means: | worrying about chances of survival |
| HIV | positive status acceptance | was easy |
| HIV | coping strategies includes: | not feeling bad |
| HIV | positive result means: | unusual mood |
| HIV | coping strategies includes: | having good image of yourself |
| HIV | coping strategies includes: | making time to rest |
| HIV | positive result means: | uncontrollable crying when alone |
| HIV | coping strategies includes: | not letting anything border me |
| HIV | emotional stress includes: | being left with the burden of taking care of children |
| HIV | coping strategies includes: | exercising |
| HIV | positive result means: | feeling bad |
| HIV | screening | tested negative several times |
| HIV | positive result means: | thoughts of receiving a death sentence |
| HIV | coping strategies includes: | eating balanced diet |
| HIV | positive result means: | crying a whole day |
| HIV | coping strategies includes: | saying no to sorrow or self-pity |
| HIV | coping strategies includes: | taking the decision am going to live, am not going to die |
| HIV | coping strategies includes: | having my husband by my side |
| HIV | positive result means: | doctors without borders restoring hope |
| HIV | coping strategies includes: | the desire to take care of the children God has blessed me with |
| HIV | positive status acceptance | was in good spirit |
| HIV | screening | gives the opportunity to start fight the disease early |
| HIV | positive status acceptance | brought me to where I am today |
| HIV | positive result means: | panicking a bit |
| HIV | positive status acceptance | means am living fine |
| HIV | positive status acceptance | means not running to churches |
| HIV | coping strategies includes: | sharing what borders you |
| HIV | coping strategies includes: | removing your mind from any deadly virus |
| HIV | coping strategies includes: | visiting one another |
| HIV | positive status acceptance | means not trying to seek help where |

| | | |
|---|---|---|
| | | there is none |
| HIV | coping strategies includes: | adhering to medications |
| HIV | coping strategies includes: | not looking down on yourself |
| HIV | coping strategies includes: | not believing that I have it, even though is there |
| HIV | positive result means: | acceptance of fate |
| HIV | positive result means: | death as the first impression |
| HIV | coping strategies includes: | having sense of purpose |
| HIV | coping strategies includes: | my dad pleading with me not for any reason get depressed |
| HIV | positive result means: | 'how I wish I don't have it' |
| HIV | coping strategies includes: | not identifying myself as someone who has AIDS |
| HIV | positive result means: | being ill treated |
| HIV | positive result means: | unbearable news - you came with someone? |
| HIV | emotional stress includes: | feeling sad when I think about it |
| HIV | coping strategies includes: | living like a normal human being |
| HIV | coping strategies includes: | having a standby HIV-positive counsellors at screening centres |
| HIV | emotional stress includes: | thinking about it when am down |
| HIV | positive status acceptance | was because there is no other choice |
| HIV | emotional stress includes: | catering for a child alone |
| HIV | coping strategies includes: | learning a craft or a trade |
| HIV | coping strategies includes: | empowering yourself |
| HIV | coping strategies includes: | support group meetings |
| HIV | positive status acceptance | was hard |
| HIV | positive result means: | moving on with life |
| HIV | coping strategies includes: | not having it in the mind always |
| HIV | emotional stress includes: | feelings of not being active and productive like before |
| HIV | positive result means: | image of death |
| HIV | positive result means: | the end |
| HIV | positive status acceptance | was another big challenge |
| HIV | positive status acceptance | not blaming God for everything |
| HIV | coping strategies includes: | the desire to live for that man who has been standing by me |
| HIV | positive status acceptance | was after a confirmation test |
| HIV | coping strategies includes: | not folding your hands |
| HIV | positive result means: | going for confirmation test |
| HIV | emotional stress includes: | thinking |
| HIV | coping strategies includes: | rest, not stressing myself |
| HIV | coping strategies includes: | taking good care of yourself |
| HIV | positive result means: | gracing up |

**PHYSICAL HEALTH IMPACTS OF HIV ON FINNISH PARTICIPANTS**

HIV medications have all kind of weird side-effects on me
HIV positive means: you can still live good healthy life

HIV medications are making me tired and affecting my body
HIV medications now make it looks like I am pregnant
HIV medications side-effects includes getting lesser
HIV positive means: giving birth to HIV-negative babies
HIV medications caused me rashes, and I have had several allergic reactions
HIV positive means: not more sick than I was before
HIV positive means: starting medications
HIV positive means: my tummy is upset at times
HIV positive means: disappearance of fat from the face and limbs and accumulated in the waist
HIV positive means: low CD4 count - around 300 instead of 750 to 1500
HIV positive means: menopause at 45
HIV cannot be easily transmitted through me because my viral load is very low
HIV positive means: low viral load
HIV vaccination can minimised the possibility of getting the disease by 40% or something
HIV led to my taking medications everyday same time
HIV positive means: not more dependent on health care than other
HIV positive means: boosting of immunity
HIV led to becoming under intense scouting
HIV positive means: CD4 count going down to as low as 100 instead of 700
HIV positive means: just being chronically ill
HIV have given me the opportunity for regular check-up
HIV positive means: giving birth to healthy babies
HIV positive means: Normal CD4 count
HIV led to my going to see the doctor every three months
HIV have given me the opportunity for other diseases to be detected very early
HIV positive means: having nightmare
HIV impacts on physical health includes: been rushed into hospital because I could not breathe
HIV led to my going to see doctor every 4, 5 or 6 months
HIV positive means: looking like a pregnant woman, when I am not
HIV positive means: several allergic reactions from medications
HIV medications have caused the fat on my face and limbs to disappear and accumulated in the waist
HIV positive means: I can travel to 3rd world countries as long as I have my supply of medicine with me

**PHYSICAL HEALTH IMPACTS OF HIV ON NIGERIAN PARTICIPANTS**

HIV positive means: I was very sick I could not even fight back anything
that get on my way
HIV positive means: being healthier than before
HIV medications caused my chick, knee, and buttock o go inside
HIV medications reduced my viral load within a year to undetectable
HIV have led to the death of those who cannot take care of themselves
HIV cure have not reached Nigeria because private hospitals
make a lot of money from medications
HIV positive means: not starting medication immediately
HIV positive means: alarm reminding me of my medications

HIV positive means: nothing, nothing bad about my health
HIV medications includes changed if they has side-effect on the user
HIV positive means: reducing in weight
HIV positive means: getting married to someone who is not HIV infected
HIV medications drops my blood level
HIV have giving me the opportunity for regular check-up
HIV positive means: low viral load, regular check-up
HIV to maintain physical health, one must take my medication morning and night
HIV positive means: looking good without a make-up
HIV positive means: normal CD4 count: they carried a test on me, and I was still doing very well, my CD4 count back then was still about [800]
HIV positive means: I was really down then, I cannot even walk, my CD4 was very low! very low almost at the point of death
HIV medications caused my stomach was big as a pregnant woman
HIV positive means: my children and husband reminding me of taking my medication
HIV medications have never had side-effect on me
HIV medications causes rashes all over the body
HIV positive means: malaria lasting longer than normal due to low immunity
HIV cure we hear rumours
HIV to maintain physical health, one must get used to medication like food
HIV to maintain physical health, one must adherence to doctors` prescriptions
HIV positive means: frequent illness
HIV medications now rationed unlike before
HIV positive means: giving birth to HIV-negative babies
HIV have giving me the opportunity for diseases to be discovered early and treated

**SOCIAL HEALTH IMPACTS OF HIV ON FINNISH PARTICIPANTS**

HIV related opportunities forgone include: saying no thanks to cheaper school health care services
HIV related stigma and discrimination led to my mum disinfecting after me and washing my clothes in a very high temperature separate from others
HIV related stigma and discrimination made my family members started to act funny including my mom, who disinfected surfaces I had used or touched
HIV related opportunities forgone includes: loss of the opportunity to get pregnant the normal way
HIV related stigma and discrimination led to a Christian mentor telling me that HIV is God's punishment and the bowl of wrath from the book of revelations and that a form of HIV has crossed itself with ebola and it spreads by sneezing
HIV related stigma and discrimination made a small town dentist confused about how to handle my appointment
HIV positive disclosure to my family was a nightmare because they thought that I was going to die soon
HIV related stigma and discrimination attitude is slowly changing
HIV positive status disclosure is problematic because is not seen like other chronic diseases
HIV related opportunities forgone includes: the loss of the opportunity to pursue a carrier in public service

HIV positive status disclosure made to strangers draws us closer, and they begin to share their own private affairs
HIV caused me to miss relationship with the opposite sex
HIV discrimination was received from a hairdresser friend who suddenly chose to wear gloves while treating my hair
HIV related stigma and discrimination was received from a hairdresser friend
HIV related stigma and discrimination made some people did not want to have anything to do with me
HIV positive status disclosure was not made to some family members
HIV related stigma and discrimination makes health care professionals to behave unusual to me during child birth
HIV made me to start using condoms constantly
HIV positive status disclosure will never be made to my employer
HIV related stigma and discrimination did not come from my good friends
HIV related stigma and discrimination made me to start keeping safe distance from men maybe keep them only as friends but that seems to be changing
HIV caused me to have harder task in finding a partner
HIV related stigma and discrimination led to a Christian mentor telling me that HIV is God's punishment and the bowl of wrath from the book of revelations
HIV related stigma and discrimination made people to almost labelling me a tramp
HIV positive status disclosure to my family was a nightmare
HIV related stigma and discrimination makes harder the task in finding a partner especially because I find it difficult to tell people about the disease relationship-wise
HIV positive status disclosure was made to some family members and closest friends
HIV related opportunities forgone include: loss of the opportunity to breast feed my baby
HIV related stigma and discrimination made people to become afraid of using the cups, cutlery or toilet I had used
HIV related stigma and discrimination led to pastor at my church pointing a finger at me from the pulpit in the presence of my new male friend and said those that are sick should not infect others
HIV impacts on faith and spirituality includes: faith and joy in Him have turned around all the trouble and made it worthwhile
HIV related stigma and discrimination made heath care professionals to stigmatise my HIV-negative daughter
HIV positive status disclosure will not be made to the world
HIV positive status disclosure have been made to many during the initial shock
HIV caused me not to behave or act as freely as I would like because am afraid to let people know my status
HIV impacts on relationships includes: becoming convinced that my man really love me;
HIV positive disclosure was not made to some family members because I don`t see the reason why they should know
HIV related stigma and discrimination led to my being embarrassed at hospital
HIV related stigma and discrimination made my family members to reject me
HIV positive status disclosure will never be made to my work colleagues
HIV related stigma and discrimination made doctors and medical attendants behave brutal to me
HIV impacts on faith and spirituality includes: trusting in God`s plan for me
HIV caused me to start living in bondage

HIV caused me to to became an escape-goat – like if I will meet a guy, and I will think that well he doesn't really like me
HIV positive status disclosure to friends was much easier
HIV related stigma and discrimination made me to be treated like a handicap by my family members and I was denied chances of normal function like driving
HIV impacts on faith and spirituality includes: some good Christian friends praying for me
HIV or AIDS laws should be amended- especially the ones that permanently see us as criminals and others as victims
HIV positive disclosure will not be made to the world because is my private thing
HIV impacts on faith and spirituality includes: having hope and faith in God
HIV caused me to loss the opportunity of having a second child
HIV related stigma and discrimination made one doctor say to me that "medical-wise there is no hope for you"
HIV related stigma and discrimination maybe caused my boss attitude to change
HIV impacts on faith and spirituality includes: realising that God is in charge of my life
HIV caused me to to be treated like a handicap by my family members
HIV caused me not to to start keeping safe distance from men maybe keep them only as friends
HIV caused me not to allow people to come very close to me
HIV positive status disclosure done repeatedly every time I go to the hospital makes me feel ashamed of myself
HIV impacts on faith and spirituality includes: being drawn closer to God
HIV related stigma and discrimination made my family a bit strange towards me
HIV positive status disclosure was difficult because of the fear of being discriminated
HIV impacts on faith and spirituality includes: believe that Jesus can and will heal me, and even if He does not, I will always serve Him
HIV impacts on faith and spirituality includes: finding a lot of comfort in my faith in Jesus
HIV related stigma and discrimination led to my mum disinfecting after me and washing my clothes in a very high temperature separate from others because she refused to get correct information, the only instruction she knows are from 1980's, my sister, who is a nurse gave them to her
HIV related stigma and discrimination attitude hurts and makes me to cry
HIV impacts on faith and spirituality includes: thanking God for my life and that of my daughter

## SOCIAL HEALTH IMPACTS OF HIV ON NIGERIAN PARTICIPANTS

HIV positive status disclosure should be made after studying a person
HIV positive status disclosure is good because it relieves one from carrying the heavy load alone
HIV discrimination is high because many see it as the worst disease
HIV or AIDS laws should be implemented - especially in taming police negative reactions towards us
HIV discrimination includes asked embarrassing questions like have you being flirting around?
HIV positive status disclosure was made to the man who wanted to marry me and he still went ahead to marry me
HIV discrimination is high but not among enlightened people

HIV positive status disclosure to a church member gave me the link to where I got my first treatment
HIV impacts on faith and spirituality includes: relying on God
HIV impacts on faith and spirituality includes: believing that I will make it
HIV positive status disclosure saves from dying silently
HIV related stigma and discrimination has reduced especially in health centres
HIV positive status disclosure unlike before is openly made by Nigerians
HIV positive status compelled us to use condoms always
HIV related stigma and discrimination starts with the individual not mixing with people
HIV positive status helped me to meet a lot of people
HIV positive status caused me to understand that my family members love me
HIV impacts on faith and spirituality includes: putting God first in everything, and having peace of mind
HIV positive status disclosure was made to the man who wanted to marry me
HIV impacts on faith and spirituality includes: acknowledging the wonders of God in my life; because some of us that started together includes now late
HIV positive status caused me to loose the opportunity of having a third child
HIV related stigma and discrimination leads to being isolated and called names
HIV impacts on faith and spirituality includes: my relationship with God changing in a way that it helps me to stay positive
HIV positive status does not hinder people from marrying HIV-negative partner, giving birth to HIV-negative children, and living happily
HIV discrimination includes: have you being flirting around? And I have always answered them I was a virgin till I got married
HIV positive status enabled me to attend seminars, workshops to learn a lot
HIV impacts on faith and spirituality includes: being drawn close to God
HIV positive status disclosure enabled me to see the marriage vow; 'for better or for worse' at work because my husband who didn`t want me to die was carrying me about, and was always with me
HIV made me not to breastfeed my baby
HIV impacts on faith and spirituality includes: relying solely on God`s grace
HIV related stigma and discrimination made a doctor reject me less than 24hours to my delivery
HIV impacts on faith and spirituality includes: knowing that I don’t have to worry about anything
HIV discrimination is high - especially at workplaces which is why some are still being sacked
HIV impacts on faith and spirituality includes: believing that I will not die
HIV related stigma and discrimination leads to self-stigmatisation
HIV impacts on relationships includes: my former husband going about to tell people that I am positive
HIV positive status disclosure will be made to my employer lest not tell comes back to hurt me
HIV strengthened the relationship in my polygamous family
HIV positive status disclosure is good because it brings out those who are hiding
HIV positive status caused me to enabled me to see the marriage vow; 'for better or for worse' at work
HIV positive status caused me to know who my true friends are
HIV positive status disclosure was not made to my elder sister because I was afraid she will tell the world
HIV positive status disclosure was immediately made to my close sister

HIV positive status caused me to asked embarrassing questions
HIV related stigma and discrimination is high
HIV positive status caused me to abandon a degree in mechanical engineering to pursue another in social work because I want to talk to people about HIV/AIDS
HIV positive status disclosure have been made to some of my fellow Muslims
HIV positive status disclosure is important so that people will stop seeing the disease as a death sentence
HIV related stigma and discrimination is high - especially at workplaces
HIV related stigma and discrimination made me travel about 8 hours trip back to Lagos shortly before my delivery
HIV related stigma and discrimination have not been experienced from health care professionals
HIV positive status disclosure is good
HIV positive status disclosure was not made to my elder sister
HIV positive status makes us to use condoms most times
HIV has taken away my opportunity to teach in private schools
HIV impacts on faith and spirituality includes: placing my life in God`s hand
HIV impacts on faith and spirituality includes: on a daily bases I speak to myself; this disease you will not take my life
HIV positive status caused me to be confronted by people who will say: they said you have AIDS
HIV positive status disclosure is made every time I see people talking negatively about the disease
HIV positive status disclosure was immediately made to all my family members
HIV impacts on faith and spirituality includes: having the courage that nothing is going to happen to me
HIV related stigma and discrimination will one day die down like that of TB and missiles
HIV impacts on faith and spirituality includes: increased interest for the God`s word and Christian songs
HIV positive status disclosure was immediately made to my God fearing husband
HIV impacts on relationships includes: ending a relationship and starting a more permanent one
HIV positive status disclosure is good when it is to the people you know
HIV positive status caused me to understand that my husband really loves me; so now I love him more than my father
HIV positive status increases the chances of finding partners

**IMPACTS OF HIV ON THE EDUCATION OF THE FINNISH PARTICIPANTS**

HIV counselling made me to understand that the disease is not that deadly
HIV medications side-effects made me slow
HIV medications side-effects makes picturing large objects difficult for me
HIV positive status leaked at school
HIV positive status has not been disclosed at school
HIV positive status has not been disclosed at school
HIV medications side-effects reduced my learning disability
HIV positive status is not affecting my studies
HIV knowledge has made the disease less scary
HIV positive status gave me the opportunity to know more people

HIV positive status enabled me learn a lot about the disease
HIV knowledge I really think that`s the best vaccination against this disease
HIV positive status did not stop me from graduating
HIV positive status has not brought to me the thought of quitting school
HIV knowledge stopped me from infecting a lot people and also my sexual behaviour changed
HIV positive status led to my dropping out of school for a semester
HIV media reporting I think it`s really outrageous
HIV positive status will never be disclosed to any student or teacher in my school because the discrimination is still very high
HIV knowledge reveals that PLWHA are not just bad people, drug addicts, homosexuals, prostitutes, etc
HIV knowledge should be share in schools by PLWHA
HIV positive status just made me study
HIV knowledge helped me to stay healthy
HIV positive status had made studying very enthusiastic
HIV media reporting I believe has made every HIV-positive person in Finland to become afraid that if something happen is their face that is going to be in the newspaper
HIV positive status has not been disclosed at school because I don`t see any reason why people in the university or anyone should know I have HIV
HIV positive status gave me the kick and boost I needed to continue studies
HIV knowledge makes us to understand that malnutrition is a bigger problem in Africa
HIV positive status made me exposed and informed
HIV positive status gave me the kick and boost I needed to continue studies at a time I don`t know if I really want to study so fast or maybe take some years off you know and try to do something lah lah lah
HIV positive status has not brought to me the thought of quitting school
HIV positive status makes remembering difficult for me
HIV positive status made me to think of ending my academic carrier
HIV knowledge helped me to move on with my life
HIV positive status led to my dropping out of school for a semester
HIV media reporting is partial and tells only tells one side of the story,
HIV positive status leaked at school for that I was embarrassed by a fellow student who refused to touch me during physical exercise
HIV positive status helped in opening my thinking to higher level
HIV positive status had made studying very enthusiastic because I want to proof to myself and the world that the disease cannot stop me
HIV positive status enabled me learn a lot about the disease
HIV media reporting should show the two sides of the story
HIV positive status paralysed my studies for about 4 years
HIV positive status gave me the kick and boost I needed to continue studies
HIV probably delayed my university enrolment
HIV positive status did not stop me from graduating
HIV positive status makes remembering difficult for me
HIV positive status gave me the opportunity to know more people
HIV positive status made me to think of ending my academic carrier
HIV positive status gave me the opportunities to attend conferences
HIV knowledge helps in eliminating funny beliefs and superstitions
HIV positive status just made me study
HIV knowledge help people to know how to treat HIV-positive people right
HIV knowledge helps people to know that they can live normal life with the disease

HIV positive status led to my dropping out of school for a semester because I was confused whether to continue or not
HIV media reporting is unethical
HIV positive status had made studying very enthusiastic
HIV positive status made me exposed and informed
HIV media reporting should not say anyone`s name, or anyone`s faces, or recognisable facts
HIV positive status paralysed my studies for about 4 years
HIV knowledge gives better prospects in life in a lot of ways
HIV positive status helped in opening my thinking to higher level
HIV positive status gave me the opportunities to attend conferences
HIV positive status is not affecting my studies

**IMPACTS OF HIV ON THE EDUCATION OF THE NIGERIAN PARTICIPANTS**

HIV positive status prevented me from attending my first choice university because my dad wanted me to stay near where I can be taken care of
HIV positive status made me skip school for 9 years
HIV positive status enabled me to attend seminars and workshops to learn
HIV counselling made me to stop bordering about the disease
HIV counselling made me to begin to take good care of myself like eat good food,
HIV positive status made me to stay extra semester in school, because I was sick and too weak to write exam
HIV medications side-effects make it very hard for me to assimilate
HIV positive status was declared at school
HIV knowledge should be obtained from schools
HIV counselling helped me see the need to start counselling the newly tested positives whenever I see them crying about their status
HIV media reporting is educative even for children
HIV medications side-effects make me forget easily
HIV media reporting is educative, but should be made more interesting
HIV positive status gave me the drive to want to know more about the disease that wants to kill me
HIV positive status gives me the drive to study harder
HIV positive status was declared at school and that made me famous
HIV knowledge contributes to the reduction of unfaithfulness in marriages
HIV positive status was confined to a school doctor during medical screening because I was afraid it will deny me admission; but funny enough HIV test was not part of the screening
HIV positive status made me to return to school to study sociology after a certificate in mechanical engineering
HIV knowledge I have received came from online and books
HIV positive status made me to choose a carrier in educating people about the disease
HIV positive status makes people run away going to school
HIV positive status has not reduce my level of academic strength in any way
HIV positive status declaration did not make me to be discriminated at school
HIV positive status made me want to upgrade my certificate so as to get a better teaching job maybe in government Para-status
HIV positive status made me to return to school to study sociology

HIV positive status made me return to School after 9 years because I want to upgrade my certificate
HIV counselling gave me the opportunity to stop seeing testing positive to the disease as the end of the world
HIV medications side-effects made me ask for a break from my supervisor
HIV counselling gave me the opportunity to learn about healthy living things; eating well, positive living
HIV media reporting is good like in the morning after listening to the news; they say HIV/AIDS is real
HIV knowledge helped me to see the need to start using my own tools when I go to do my hair
HIV positive status has not affected my studies
HIV positive status made me return to School after 9 years
HIV counselling made me to stop seeing the disease as a big deal
HIV positive status has not reduce my level of academic strength in any way instead I will say my drive became stronger as a matter of fact, I decided to do more to proof to my dad that HIV is not limiting me in any way
HIV knowledge through other people`s experience and story have given me the courage to move on with my life
HIV positive status did not stop me from school because I didn't see that as a challenge
HIV knowledge should be taken to local communities
HIV positive status increased my knowledge in general
HIV positive status has helped me to know more people
HIV positive status did not stop me from living normal life in campus
HIV knowledge should be shared through media, adverts, billboards, and sending people to the communities

**IMPACTS OF HIV ON THE PRODUCTIVITY AND FUTURE GOALS OF FINNISH PARTICIPANTS**

HIV medications side-effects now makes me get tired easily due to their neurological side effects
HIV positive status gave me the strength for dealing with people`s attitudes
HIV medications side-effects now makes me get tired easily due and has thereby affected my productivity
HIV positive status gave me the boost like to do something with my life
HIV positive status makes me worry that somehow someday people somewhere people will find out
HIV medications side-effects have made me now 75% normal, but used well and wisely, this is enough
HIV medications side-effects hopefully will become lighter
HIV positive status gave me the kick to do something with my life
I don`t think I will die because of my HIV
HIV medications side-effects makes me worry about how long body can support 12 pills a day
Am quite sure someday I will have husband or someone to share this life with despite my HIV
HIV positive status has taken away the opportunity to pursue a carrier in public service
I am afraid of what will be the reaction of my one year and half daughter when I will tell her about my HIV

I suffer slight discrimination at workplace because of my HIV
I have the hope of a productive future despite my HIV
Am worried if I will get all the benefits my future holds for me because of my HIV
Am worried about how long my body will be able to cope with the side-effects of the medications for HIV
I hope that my body will be able to cope with the medications for HIV
HIV positive status has not affected my productivity at all
I am worried that people will find out about my HIV
HIV positive status will not affect my work because in Finland without my permission the doctor cannot give it to my employer
HIV positive status has made my future unclear I have a steady job despite my HIV
I have the hope of being financially independent despite my HIV
HIV positive status makes me afraid of being hired
I will give birth to a HIV-negative child despite my HIV
At work when I am seated doing nothing I often easily fall asleep because of my HIV
I enjoy my studies despite my HIV
HIV positive status more goals and reasons to do something
HIV positive status has made me to become afraid of being asked to defend why I am occupying a position despite positive status
I have faith and hope despite my HIV
I am afraid I may be lonely in the future because of my HIV
HIV medications hopefully will reach the people who need them
I am afraid of being rejected if people find out about my HIV
I have hope for better drugs and cure for HIV
HIV positive status have made me more driven to do stuffs after I found out
HIV positive status gave me goals
I am afraid fellow students will find out about my HIV
I am afraid that my colleague who was once a social worker will tell people about my HIV
I think I will enjoy my work someday despite my HIV
People have seen me in relatively good health for nearly 20 years despite my HIV

## IMPACTS OF HIV ON THE PRODUCTIVITY AND FUTURE GOALS OF NIGERIAN PARTICIPANTS

I lost a teaching job in a private school because of my HIV status
HIV positive status makes me go extra miles to be very successful in life
HIV positive status has not quench my desire to be the best designers in the world, I still want to learn fashion designing
HIV positive status made me to choose a carrier in educating people about HIV
I am still struggling to contribute in the family, to see the well being of the family, I did not abandon it for the man alone despite my HIV
HIV cure hopefully will come while am still alive
I still having the drive to pursue my carrier gives me hope despite my HIV
I have hope for a bright future despite my HIV
HIV positive status makes me go extra miles to be very successful in life through doing what people see extraordinary
HIV medications care me
HIV positive status does not pose a barrier to carrier opportunities
HIV positive status made me to choose a carrier in educating people about HIV
HIV positive status does not pose a barrier to carrier opportunities because as far as I am healthy, looking healthy, there is no where I cannot work
HIV positive status made me to choose a carrier in educating people about HIV that is why I got a lot of this training last week in Abuja
Since I know my rights, I have nothing to worry about despite my HIV
Economic hardship makes me to solicit for my children school fees because of my HIV
Since HIV-positive people marry HIV-negative and give birth to HIV-negative babies, I have nothing to worry about despite my HIV
Working prevent people from thinking about HIV
HIV positive status should not stop people from knowing the exact profession they want to go to after school
HIV positive status gave me the opportunity to volunteer for one HIV/AIDS organisation
Now I can`t do any strenuous work because of my HIV
Through the grace of God I hope to see my children`s children despite my HIV
I don’t work as I use to work because of my HIV-positive status

## TRANSFORMATIONS IN FINNISH PARTICIPANTS AFTER TESTING POSITIVE TO HIV

I have come to realise that like diabetics I can live like normal people despite my HIV Positive Status
My HIV Positive Status made me to start considering what I do to my body
I love sweet things, but I try very hard not to eat that very much because of my HIV Positive Status
My HIV Positive Status made me start doing sports
My HIV Positive Status made me to start going to theatre
My HIV Positive Status changed to a person who tries to eat fruits and vegetables
My HIV Positive Status made me to start trying to eat healthy
My HIV Positive Status made me to start trying to exercise, but well try!
My HIV Positive Status made me to stop drinking or partying

My HIV Positive Status made me to only think about finding a job that will help save the world in some way
My HIV Positive Status changed me to a person who always tries to stay healthy
My HIV Positive Status made me to start trying to eat and sleep well
My HIV Positive Status made me to realise that work isn`t my life or money or nothing like that but I always little hippy
My HIV Positive Status made me believe that I cannot do drugs again
I don`t stress so much, I don`t push so much because of my HIV Positive Status
My HIV Positive Status made me realised that I will live long if I live healthy
My HIV Positive Status added to loss interest in money and everything like how the world work
I have been vegetarian for about 15 years and I will remain a vegetarian because of my HIV Positive Status
My HIV Positive Status made me to start swimming, gym, cycling, aerobics, and Pilates
I exercise, I go out, move my dog, I like walking because of my HIV Positive Status
My HIV Positive Status made me to know that I should begin to take things more easy
My HIV Positive Status made me to start taking more care of my health now
My HIV Positive Status made me to start resting well
My HIV Positive Status made me realise the fact that if I eat healthy I will live healthy
My HIV Positive Status made me begin to keep my spirits high
If I have really difficult time in school like too much to do, I just take time out if I need to; am not so hard on myself because of my HIV Positive Status
My HIV Positive Status changed to a person who tries to eat like well balanced
My HIV Positive Status has put new perspective to my life
My HIV Positive Status has made me a very hygienic person
My HIV Positive Status added to thinking less about productivity
My HIV Positive Status made me to stop smoking cigarette
My HIV Positive Status made me to become more careful with my body
I don`t drink at all, never, I don`t think I will ever again drink because of my HIV Positive Status
My HIV Positive Status made me to stop judging other people easily
My HIV Positive Status made me to realised that I only have this one life and I need to live it as good as I can
My HIV Positive Status made me to start seeing my body as more frail than that of normal people
My HIV Positive Status made me a little bit better person than I will be without it
My HIV Positive Status made me to start seeing myself as a warrior princess
My HIV Positive Status made me to start eating healthier diet

**TRANSFORMATIONS IN NIGERIAN PARTICIPANTS AFTER TESTING POSITIVE TO HIV**

I try to reduce my working so that I will have enough rest because of my HIV Positive Status
I always sleep under mosquito treated net because of my HIV Positive Status
My HIV Positive Status made me to start staying healthy
My HIV Positive Status made me to start relaxing
My HIV Positive Status made me to stop taking soft drinks
Now I use my own hairdressing tools because of my HIV Positive Status
My HIV Positive Status changed my wayward lifestyles

My HIV Positive Status made care very much about where I sleep; not expose myself to mosquito bite
I have stopped going to saloon because of my HIV Positive Status
My HIV Positive Status made me to stop sharing sharp objects
My HIV Positive Status made me to begin to eat beans long before bedtime
My HIV Positive Status made me to begin to see things differently
My HIV Positive Status made me to stop borrowing eyes lips from my sisters
My lifestyle has been changed because of my HIV Positive Status
Now I care so much to avoid mosquito bite so that I don't have malaria because of my HIV Positive Status
My HIV Positive Status made my dad to sponsor my trip abroad
Now I am 100% careful what I take because of my HIV Positive Status
My HIV Positive Status made start eating more balanced diet
My HIV Positive Status has given me additional privileges
My HIV Positive Status changed my quarrelsomeness
My HIV Positive Status changed my life for better
At times when you are working your body system will tell you, you are tied, immediately I feel so I will stop whatever am doing because of my HIV Positive Status
My HIV Positive Status made me a better cook, because I use to, am like I feed on junk, bread & tea, bread & sardine, but when I tested positive to HIV, I got to know the need to eat well, then I learnt to cook, and I improved
My HIV Positive Status has many good aspects
I can`t stay anywhere; where I feel there are mosquitoes because of my HIV Positive Status
Now I am 100% careful about protecting my children and husband because of my HIV Positive Status
My HIV Positive Status changed my life completely
Now I am 100% careful my environment because of my HIV Positive Status
My HIV Positive Status made me to realise that I should avoid malaria which kill fasters than HIV
My HIV Positive Status made to start cooking my meal, I cook myself and I enjoy doing it
I pay more attention to my surroundings; you know keep the place mosquito free if it is possible because of My HIV Positive Status
My HIV Positive Status made me to start receiving extra attention from my dad in the sense that I do not lack anything
My HIV Positive Status has opened doors of opportunities for me
My HIV Positive Status made to start taking enough rest
My HIV Positive Status has made little or no change in me
My HIV Positive Status made me to planning my life
My HIV Positive Status made to start living fresher life instead of living by other people`s dictate
My HIV Positive Status changed me to the point that I always keep to time, whatever am doing
My HIV Positive Status made to stop sharing tooth brush with my sisters
I joined the anti-AIDS club in my school that I thought I have no business with I voluntarily after I tested positive to my HIV Positive Status
I don`t use to like fruits before, but now I eat them because of my HIV Positive Status
I don't like taking a lot of water, but I do that now because of my HIV Positive Status
I try as much as possible to avoid any opportunistic infection because of my HIV Positive Status

I don’t like exercising or walking too long, I do that now because of my HIV Positive Status
Now I eat fruits more than before, I can`t go a day without fruit, and I eat more of vegetable because of my HIV Positive Status
My HIV Positive Status changed my way of seeing things
My HIV Positive Status made me to start planning for my children in case if anything happen to me
My HIV Positive Status has drawn my attention to my health